Universitat Internacional de Catalunya

Tesis doctoral

Dos miradas sobre el deseo de adelantar la muerte, la dignidad y la autonomía en pacientes al final de la vida.

De la investigación empírica, a la reflexión filosófica

Andrea Rodríguez Prat

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Durante mi estancia de investigación en Holanda, fue verdaderamente revelador el hallazgo de este poema de León Felipe. Ante el perfil omnipresente del Dom de Utrecht, tantas veces pensé en esta cadena de hombres y mujeres que forman parte de mi vida y de esta tesis:

Hombres
sobre hombros
de otros hombres;
hombres
con hombros
para otros hombres;
hombros,
hombres,
hombros,
torres.
Un día ya no habrá estrellas lejanas
ni perdidos horizontes.

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A modo de prólogo

A principios del año 2014, cuando empecé el Máster de Investigación en Enfermería y Salud, mi profesor de antropología, entonces, y director actual de tesis pidió a las ocho enfermeras, una psicóloga y a mí (“humanista”), alumnas de ese máster, que escribiéramos un ensayo sobre lo que puede aportar la antropología o la filosofía a la enfermería.

Hace ya más de tres años escribí que para una persona que no ha estudiado Enfermería, y que hasta ese momento no había tenido ningún contacto con el ámbito clínico, resultaba difícil reflexionar sobre qué pueden aportar la antropología a las ciencias de la salud porque mi respuesta espontánea era ‘todo’.

La enfermería no puede desvincularse del trato con las personas y la filosofía ha reflexionado desde hace muchos siglos sobre quién es la persona, qué lugar ocupa en el mundo, cuáles son sus deseos y temores, qué dimensiones subyacen en ella, hacia qué fin tiende, etc. En consecuencia, podría decirse que la enfermería y la filosofía tienen un objeto-pasión en común que es el ser humano. Sin embargo, la aproximación que hacen cada una de ellas puede ser, a priori, muy distinta.

Una primera cuestión a favor de la filosofía es que proporciona un horizonte de sentido que permite trascender la ‘acción técnica’ bajo una perspectiva trascendente porque, cuando no es reduccionista, puede enseñar que la persona tiene más dimensiones que las que simplemente aparenta.

La enfermería, si no es con las luces de una mirada antropológica, no puede reconocer en sus pacientes la imagen que la filosofía puede construir de él. Aparentemente, quizá es verdad que el ser humano se ve como ‘un cuerpo’; pero no es la evidencia empírica la que dice que no es solo eso, sino que es el pensamiento filosófico el que permite despegarse “de la carne y de los huesos” para ir un poco más lejos.

La actitud de quien ve el mundo con una mirada filosófica debería conducir a la sabiduría: integración vivida de los distintos niveles de saber, aprender a aplicar el entendimiento a cada acción particular como resultado de una ponderación prudente y libre. En este sentido, la filosofía se presenta para los profesionales de la enfermería como la amalgama capaz de vincular diferentes experiencias y generar nuevas sinergias de pensamiento y de acción en continuo crecimiento porque se ha reflexionado sobre ellas. Y no solo eso, sino que se presenta como la herramienta para descubrir la naturaleza del ser humano en los rostros que encuentra cada día, para detectar la verdad en los misterios de la vida y de la muerte, en cada nacimiento y en cada fallecimiento, en la alegría y en el dolor. Es decir que este sentido que otorga la filosofía se da a dos niveles. El primero, en cuanto a ciencia que se interroga por las primeras y últimas causas y trata de obtener una respuesta. El segundo, en cuanto a plataforma de conocimiento que intenta reconocer el significado de la realidad.

Después de este tiempo, después de haber tratado con profesionales de la salud y haber conocido el mundo clínico un poco más de cerca se me ha ido haciendo evidente todo lo que la enfermería –y las ciencias de la salud– pueden enseñar a la filosofía, a la antropología filosófica y a las humanidades.

Si desde la antropología alguien profundizara sobre el amor, podría correr el riesgo de quedarse en un marco solamente teórico. Sin embargo, los enfermeros, en el mejor de los casos, comprenden muy bien cómo vivir ese amor, por ejemplo, a través del cuidado de la gente o saliendo al encuentro de los más vulnerables. La enfermería es capaz de encarnar estos valores con los que un filósofo quizá piensa y profundiza pero quizá no acierta a poner en práctica.

Aunque sigue siendo tarea de la filosofía aportar los valores que sin duda ayuden a trascender la rutina, es enriquecedor reconocer que existe una retroalimentación entre estas disciplinas: la filosofía puede aportar una mirada multidimensional y profunda sobre quién es la persona más allá de lo que aparentemente se pueda observar y la enfermería puede enseñar a aterrizar ese conocimiento y plasmarlo en una realidad tangible y cotidiana.

Sin miedo a exagerar, podría afirmar que, profundizar en el ámbito de la salud ha sido lo que me ha hecho descubrir el valor de las humanidades: poder responder a las necesidades e inquietudes del ser humano. Y, precisamente éste ha sido el objetivo implícito de esta tesis. Como reflexión sobre lo que pueden aportar las humanidades a la sociedad y al mundo de la salud en particular, escribí junto con la Dra. Cristina Monforte la carta editorial, que a continuación se presenta, que fue publicada en *The Lancet* (Rodríguez-Prat & Monforte-Royo, 2017). Simplemente el hecho de que fuera publicada en esta revista clínica me parece indicativo de la importancia que, en efecto, pueden tener las humanidades médicas y del impacto positivo que pueden tener tanto en los profesionales de la salud como en los pacientes.

25 years after *Intoxicated by My Illness*. Challenges for Medical Humanities

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Communicating with patients at the end of life is regarded as a difficult task, and speaking openly about death is often avoided.[1,2] Around 50% of patients are informed about their diagnosis and prognosis in many European countries. “Silence conspiracies” are fairly common.[3] They are defined as the agreement between health professionals (HP) and relatives/carers to hide from the patient information related to their clinical condition.

Studies which investigated the desire for death (DD) agree on the importance of communication between HP and patients for preventing and addressing the DD. Talking with the patients and giving them the opportunity to identify the reason for the DD is critical to formulating an adequate response when dealing with the specific issues that underlie this desire and to relieve suffering.[4]

What is it that prevents an adequate communication in the clinical context? Why avoiding to talk about death? Is it because we do not know how to address it anymore? Why is silence the alternative to facing transcendental issues?

The year 2017 marks 25 years since the publication of *Intoxicated by My Illness* by Anatole Broyard.[5] His words are still an excellent means of presenting the humanities as the source that inspires human experiences. What we are looking for in a doctor is for them to be someone “who is a close reader of illness and a good critic of medicine […] a doctor who is not only a talented physician, but a bit of a metaphysician, too. Someone who can treat body and soul. There’s a physical self who’s ill, and there’s a metaphysical self who’s ill […] He should be able to imagine the aloneness of the critically ill […] I want him to be my Virgil, leading me through my purgatory or inferno, pointing out the sights as we go”.

The humanities can be the basis on which to shape the language of mourning, of suffering, of death “entering the ill person’s condition [and] looking at it from all sides, from the inside”.[5] They could create narratives to help interpret the illness in order to detoxicate it and give it meaning. They could find the forgotten words patients might need to hear for them to create their own stories. They could give HP the tools to be not only Virgils, but Odysseuses looking for their origin, or Ivan Ilichs unveiling gestures of care and comprehension on the deathbed.

REFERENCES

1. Villavicencio-Chávez C, Monforte-Royo C, Tomás-Sábado J, et al. Physical and psychological factors and the wish to hasten death in advanced cancer patients. Psychooncology. 2014;23:1125–32.

2. Oosterink JJ, Oosterveld-Vlug MG, Glaudemans JJ, et al. Interprofessional communication between oncologic specialists and general practitioners on end-of-life issues needs improvement. Fam Pract. 2016.

3. Numico G, Anfossi M, Bertelli G, et al. The process of truth disclosure: an assessment of the results of information during the diagnostic phase in patients with cancer. Ann Oncol. 2009.

4. Dierckx de Casterlé B, Verpoort C, De Bal N, et al. Nurses’ views on their involvement in euthanasia: a qualitative study in Flanders (Belgium). J Med Ethics. 2006;32(4):187–92.

5. Broyard A. Intoxicated by my Illness. Intoxicated by my illness and other writings on life and death. New York: Fawcett Columbine, 1993:40-50.

Índice general

Resumen

En el ámbito de final de vida, no es infrecuente que algunos pacientes expresen deseo de adelantar la muerte como manifestación de sufrimiento relacionado con múltiples factores. Algunos estudios han subrayado la importancia del sentido de dignidad personal y de la autonomía o control como factores destacados en relación a este deseo. Sin embargo, frecuentemente, estos conceptos aparecen de forma equívoca. Mantener cierto control sobre las circunstancias ha resultado ser una forma de disminuir el sufrimiento por esta pérdida de autonomía. No obstante, no es clara la relación existente entre la dignidad percibida y autonomía a la luz de la experiencia de los propios pacientes.

Asimismo, diferentes autores han puesto en diálogo la reflexión filosófica y los estudios empíricos llevados a cabo en el campo de las ciencias de la salud. En este sentido, la antropología y filosofía médicas se han extendido como ciencias que se han preguntado sobre la vivencia de la enfermedad desde el punto de vista de los pacientes y de los profesionales de la salud. De forma particular, la fenomenología ha aportado temas filosóficos valiosos para la reflexión clínica y estructuras claves para entender el mundo como experiencia dada a un sujeto intencional capaz de determinar su significado.

Esta tesis doctoral pretende profundizar sobre el deseo de adelantar la muerte, la dignidad percibida y autonomía en pacientes al final de la vida y reflexionar sobre ellos desde el punto de vista de los datos empíricos y de la reflexión filosófica-antropológica, mediante cinco estudios.

Los objetivos de estos estudios fueron efectuar una revisión sistemática y meta-etnografía de los estudios cualitativos primarios sobre la relación entre dignidad percibida y autonomía en pacientes al final de la vida y sobre la experiencia del deseo de adelantar la muerte desde la perspectiva de las personas con enfermedades avanzadas. Analizar desde una perspectiva fenomenológica, particularmente desde las nociones filosóficas desarrolladas por Kay Toombs, la experiencia vivida de la dignidad percibida y autonomía a la luz de los estudios cualitativos publicados. Examinar las nociones contemporáneas sobre la fenomenología y antropología de la enfermedad y del morir atendiendo a la medicalización, a los valores y presupuestos morales de los pacientes que expresan deseo de adelantar la muerte a la luz de los estudios cualitativos publicados sobre este fenómeno. Y, de forma específica, comparar el fenómeno de la interrupción voluntaria de la hidratación y de la alimentación a la luz de los resultados de los estudios cualitativos sobre el deseo de adelantar la muerte.

Los hallazgos obtenidos apuntan hacia el hecho de que, tras el análisis de los estudios sobre dignidad y autonomía, todas las vivencias de los participantes estuvieron penetradas por el hecho de padecer una enfermedad, por la influencia del contexto social y por el impacto en la identidad personal. Partiendo de las categorías halladas en esta revisión sistemática, observamos que es posible llevar a cabo una reflexión fenomenológica a través de las

nociones de cuerpo objetivo-vivido y a través de la estructura yo-cuerpo-mundo-otros.

El deseo de adelantar la muerte en pacientes con enfermedad avanzada no puede entenderse fuera de la experiencia de sufrimiento, siendo éste un requisito necesario para su aparición en esta población. Detrás de cada expresión de deseo de morir existen unas razones y significados que permiten comprender el deseo de morir en los pacientes que lo presentan.

El análisis de los verbatims de los estudios cualitativos sobre el deseo de adelantar la muerte permiten observar una dimensión socio-antropológica sobre la vivencia del sufrimiento y del morir que presupone la atribución de un valor sobre uno mismo, sobre los demás y sobre el valor de la vida en el marco de la medicalización que ayudan a comprender desde un punto de vista biográfico y social el significado de este deseo de morir.

La interrupción voluntaria de la hidratación y de la alimentación puede entenderse como una expresión del deseo de adelantar la muerte a la luz de los estudios cualitativos sobre este fenómeno que debe ser abordada clínicamente como una manifestación de sufrimiento no implícito.

En conclusión, puede decirse que la dignidad es percibida como una cualidad multidimensional y dinámica, y es experimentada como una forma de identidad personal. Analizar la experiencia vivida de los pacientes a través de las verbatims de los estudios cualitativos, desde la perspectiva empírica y fenomenológica, permite profundizar en su experiencia y ayudar a comprender mejor la enfermedad desde un punto de vista vivencial.

Asimismo, puede concluirse que la expresión del deseo de adelantar la muerte en pacientes con enfermedad avanzada apunta hacia la necesidad de explorar individualmente las razones, los significados y las funciones atribuidos, para comprender la naturaleza de este deseo en cada paciente y poder diseñar planes de atención individualizados.

El impacto de la medicalización está presente en la experiencia de los pacientes que expresan este deseo y modula las representaciones sobre el sufrimiento, el proceso de final de vida y la muerte. Conocer la experiencia de estos pacientes, sus valores y presupuestos puede contribuir a que recobren el valor que se atribuyen a sí mismos y generar un impacto positivo en el imaginario social.

Teniendo en cuenta que tanto la expresión del deseo de adelantar la muerte como la expresión de pérdida de percepción de dignidad están condicionadas por diversos factores, desarrollar planes de cuidado que consideren ‘la mirada fenomenológica’ así como la biografía de los pacientes redundará en una mejora de la calidad de vida.

Abstract

In the context of the end of life, it is not infrequent for some patients to express the wish to hasten death as a manifestation of suffering related to multiple factors. Some studies have highlighted the importance of the sense of personal dignity and autonomy or control as related factors. However, these concepts are often used ambiguously. Maintaining a certain level of control over the circumstances is a way of reducing suffering for this loss of autonomy. However, it is unclear what relationship exists between perceived dignity and autonomy in light of patients' experiences.

In the same way, various authors have linked the philosophical reflection and the empirical studies carried out in the field of health sciences. In this sense, medical anthropology and philosophy have grown as sciences and have reflected upon the experience of illness from the point of view of patients and healthcare professionals. In particular, phenomenology has provided valuable philosophical themes for clinical reflection and key structures to understand the world as a lived experience by an intentional subject capable of determining its meaning.

This doctoral thesis aims to examine the wish to hasten death, perceived dignity and autonomy in patients at the end of life in more detail and to reflect upon them from a point of view of empirical data and philosophical-anthropological reflection, through five studies.

The objectives of these studies were: to carry out a systematic review and meta-ethnography of the primary qualitative studies about the relationship between perceived dignity and autonomy in patients at the end of life and about the experience of the wish to hasten death from the perspective of people with advanced illness; to analyse the experience of perceived dignity and autonomy in light of the qualitative studies published from a phenomenological perspective, in particular the philosophical notions developed by Kay Toombs; to examine the contemporary notions about phenomenology and anthropology of illness and dying bearing in mind medicalisation, the values and moral assumptions of patients who express the wish to hasten death in light of the qualitative studies published about this phenomenon; and, specifically, to compare the phenomenon of voluntary stopping eating and drinking in light of the results of the qualitative studies about the wish to hasten death.

The findings point to the fact that, through the analysis of the studies about dignity and autonomy, all participants' experiences were affected by the fact that they suffer from an illness, by the influence of the social contact and by the impact of personal identity. Based on the categories found in the systematic review, we observed that it is possible to carry out a phenomenological reflection through notions of objective-lived body and through the structure self-body-world-others.

The wish to hasten death in patients with advanced illness cannot be understood without the experience of suffering given that, this is a necessary

requisite for its emergence in this population. Behind each expression of the wish to hasten death, there are reasons and meanings which allow us to understand the wish to hasten death in the patients that present it.

The analysis of the verbatims from the qualitative studies about the wish to hasten death allow us to observe a socio-anthropological dimension about the experience of suffering and dying which presupposed the attribution of a value to life in the framework of medicalisation which helps to understand from a biographical and social point of view the meaning of the desire to die.

Voluntary stopping eating and drinking can be understood as an expression of the desire to die in light of the qualitative studies about the phenomenon that should be addressed clinically as a manifestation of non-implicit suffering.

In conclusion, it can be said that dignity is perceived as a multidimensional and dynamic quality and is experienced as a form of personal identity. Analysing the experience of patients through the verbatims of the qualitative studies, from an empirical and phenomenological point of view helps to better understand the illness in terms of experience.

Furthermore, it can be concluded that the expression of the wish to hasten death in patients with advanced illness suggests a need to explore the reasons, meanings and functions attributed to this wish in order to understand the nature of this wish in each patient and to be able to design individualised care plans.

The impact of medicalisation is present in the experiences of patients who express the wish to hasten death and it regulates representations of suffering, the process of the end of life and death. Knowing and understanding these patients' experiences, their values and their assumptions can contribute to them regaining the value that they give themselves and generate a positive impact on the social imaginary.

Bearing in mind that both the expression of the wish to hasten death and the expression of a perceived loss of dignity are influenced by various factors, developing care plans that take into account the "phenomenological perspective" as well as the biography of the patients would result in an improvement of quality of life.

Capítulo 1. Introducción. El encuentro de dos miradas: de la investigación empírica, a la reflexión filosófica

En los últimos años, estudios en el contexto de final de la vida han destacado la importancia de respetar a la persona con sus valores y creencias (Abiven, 1990; Casell, 1982; Karel, 2000; Latimer, 1991; Rendtorff, 2002), han explorado cuál es la experiencia vivida de los pacientes a causa de su enfermedad (Carel y Cooper, 2013; Charmaz, 1983; Delmar et al., 2005; Kleinman, 1988; Paterson, 2001; Toombs, 1988) y qué elementos influyen sobre la percepción de la propia identidad (Chochinov, 2002; Chochinov et al., 2002; Emanuel y Emanuel, 1998; Steinhauser et al., 2000). En este contexto, no es infrecuente que algunos pacientes expresen cierto deseo de adelantar la muerte (DAM) como manifestación de un sufrimiento multidimensional relacionado a su vez con múltiples factores (Monforte-Royo et al., 2011; Monforte-Royo et al., 2012). Tal como han señalado algunos autores, el expresar el DAM no implicaría necesariamente la petición de ninguna intervención para acabar con la propia vida (Monforte-Royo et al., 2012) sino que podría entenderse como una forma de respuesta a este sufrimiento.

Algunos estudios han relacionado este DAM con la pérdida de percepción de dignidad (Chochinov et al., 2008; Monforte-Royo et al., 2012) y han destacado la importancia del sentido de dignidad personal como factor clave en el cuidado de los pacientes y como una cualidad que hay que preservar en este periodo de especial vulnerabilidad (Chochinov, 2002, 2004, 2007; Chochinov et al., 2002; Enes, 2003; Jacelon, 2003; Jacobson, 2009a). No obstante, a pesar de la amplia literatura en el ámbito de la salud sobre el tema, muchos autores destacan el carácter impreciso y equívoco de dignidad (Haddock, 1996; Jacobson, 2009a; Johnson, 1998; Pullman, 2004; Sulmasy, 2005, 2013); así como la dificultad que supone encontrar consenso sobre su significado o sobre el significado que los pacientes atribuyen al término dignidad.

Otro de los conceptos clave relacionado con la emergencia de un posible DAM es la autonomía, entendida y relacionada también con control, autodeterminación o toma de decisiones. Del mismo modo que se ha hecho con *dignidad*, diversos estudios han tratado de analizar qué se entiende por estas nociones y con qué factores están relacionadas (Bakitas, 2005; Blackhall, 1995; Delmar, 2013; Drought y Koenig, 2002; Lavoie, Blondeau, y Picard-Morin, 2011; McGrath, 1998; McNamara, 2004; Requena Meana, 2008; Ruhnke, Wilson y Akamatsu, 2000; Schicktanz, Raz y Shalev, 2010; Schroepfer, Noh y Kavanaugh, 2009; Volker, 2001; White y Callahan, 2000; Wilson, Ingleton, Gott, y Gardiner, 2014; Winzelberg, Hanson y Tulsky, 2005). Sin embargo, su significado es complejo y poliédrico, a pesar de que aparezcan en los argumentos clave de algunos de los debates candentes de la actualidad. Por ejemplo, en el informe que publica anualmente Oregón (Public Health Division, 2017), estado donde se aprobó el suicidio asistido en 1994 y es referente en esta práctica, la pérdida de autonomía es la causa principal por la cual, las personas que desean morir lo solicitan. Del total de las 1127 personas que murieron bajo el *Dying with Dignity Act* [Ley sobre el Morir con Dignidad] hasta enero del 2017, el 91,4% determinó poner fin a su vida por esta pérdida de autonomía.

El discurso a favor de la ‘muerte con dignidad’, que cobró fuerza en la década de los 70 en el ámbito americano con los casos de Karen Ann Quinlan y más tarde de Nancy Cruzan (Crigger et al., 1990; Kass, 1993; Kaufman, 2000; Sullivan, 2002), es el que ha planteado de una forma más contundente la relación entre dignidad y autonomía en el contexto de final de vida. La autonomía, en este ámbito, aparece como fundamento de la dignidad, y los valores personales de los pacientes son resaltados como absolutos. Algunos estudios de diseño cuantitativo han analizado cuál es la relación que existe entre ambas variables (Chochinov et al., 2002; Coenen, Doorenbos y Wilson, 2007; Doorenbos, Wilson y Coenen, 2006; Hack et al., 2004; Hall et al., 2014). Y en estudios de corte cualitativo, tanto los focalizados en la percepción de la dignidad (Brown, Johnston y Östlund, 2011; Chochinov et al., 2002; Enes, 2003; Franklin, Ternestedt y Nordenfelt, 2006; Pleschberger, 2007) y en el control (Schroepfer et al., 2009; Volker, Kahn y Penticuff, 2004a, 2004b), como los que exploraron el deseo de adelantar la muerte (Coyle y Sculco, 2004; Dees et al., 2011; Lavery et al., 2001; Mak y Elwyn, 2005; Pearlman et al.,

2005) o las vivencias asociadas al suicidio asistido o eutanasia, también se describió esta relación.

No cabe duda de que en la conexión entre los conceptos de dignidad y autonomía cobran especial relevancia los aspectos culturales. En las últimas décadas, en el contexto de la cultura occidental y desde el punto de vista de la historia de las mentalidades, se ha producido un cambio radical en cómo se entienden el dolor, el sufrimiento y la muerte. En numerosos países, los debates clínicos, éticos y públicos acerca de la eutanasia y el suicidio asistido han ido en aumento. Con frecuencia la defensa de estas prácticas es justificada desde unas coordenadas antropológicas y culturales que defienden valores, como el de la autonomía, como irrenunciables. En un estudio de van Wijngaarden et al. (2015), por ejemplo, se observó que algunos de los ancianos a los que habían entrevistado y que habían solicitado eutanasia o suicidio asistido no lo habían hecho debido a su sufrimiento físico o a causa de depresión, sino por considerar que no 'valía la pena seguir viviendo'. La extensión de expresiones como muerte autoproclamada, autoelegida o autodeterminada son indicativas de este cambio de mentalidad y actitud ante la muerte que, asimismo, normaliza el acceso a la muerte como acto voluntario. La forma en la que hablamos sobre la muerte es indisociable de la construcción de un imaginario colectivo[1] sobre el sufrimiento y el morir. En el caso de las sociedades occidentales, este imaginario –como veremos con más detalle en la sección 7.4.2 y en el cuarto artículo de la tesis– presupone, por un lado, el deseo de autonomía y autodeterminación, el ideal de una vida auténtica; y, por otro, el rechazo u ocultación del sufrimiento y de la muerte. De esta forma, algunos estudios sociológicos observan que, en las sociedades occidentales, puede darse cierta tendencia a vivir al margen de la muerte, obviando que el ser humano es mortal y finito (Ariès, 2005; Arregui, 1994; Baudrillard, 1980; Bayés, 2003; Jiménez Aboitiz, 2012; Walter, 1994).

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[1] El concepto de imaginario fue acuñado por el Edgar Morin en la década de los 60. Este término hace referencia al conjunto de representaciones culturales, símbolos, costumbres, recuerdos, etc. que tienen un significado común para todas las personas que forman parte de una comunidad.

La vivencia del sufrimiento, el dolor, la enfermedad y la muerte tienen una significación específica dependiendo del marco referencial que le proporciona cada cultura particular (Illich, 1976; Le Breton, 1999; Morris, 1991). Cuando el hombre y la mujer modernos dicen hoy “sufro, no quiero vivir así”, lo dicen desde el peso de la tradición cultural, religiosa, social, etc.[2] que les antecede. Si bien es verdad que cualquier expresión fruto de las experiencias humanas más profundas –como lo es el sufrimiento– ha sido registrada y representada a lo largo de la historia, la forma en que se ha hecho y los significados que se le han atribuido pueden variar. Como dijo el médico y antropólogo David Morris (1991):

> “La comprensión del dolor requiere muchos tipos de conocimiento, pero el que más solemos desdeñar o ignorar, como he mostrado, concierne al vínculo que une dolor y significado. El punto que quiero destacar es que la humanidad –en todas las culturas y en todos los tiempos– ha comprendido el dolor, de modo persistente, como un suceso que exige interpretación. El dolor no solo hiere, sino que suele frustrar, confundir, chocarnos. Parece que no podemos sufrir un dolor a secas, sino que casi siempre nos vemos obligados a buscarle sentido” (p. 19).

Como puede observarse, el dolor no solo es padecido orgánicamente sino que también es interpretado y vivido biográficamente por la persona que lo sufre. De esta forma, la presencia de nuevos valores como la autonomía, autodeterminación, autenticidad, individualismo, etc. en la sociedad, en los medios de comunicación, en los medios académicos, en la cultura popular de masas influyen en cómo entendemos las vivencias, las actitudes y los deseos de los pacientes manifestados en los contextos clínicos.

En los países occidentales la representación social de estas realidades –cómo la sociedad las concibe y experimenta– está estrechamente relacionada con el nacimiento de la clínica moderna y con la medicalización (Foucault, 1978). Por medicalización podemos entender “el proceso a través del cual problemas que no son médicos pasan a ser comprendidos y tratados como si lo fueran” (Conrad, 2008, p. 5). Así, la vida, los procesos de enfermedad, la

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[2] En esta tesis, aunque en algunos casos se detalla de forma explícita, las nociones de tradición, sociedad o cultura hacen referencia a la civilización occidental, cosmopolita, tecnológica.

muerte, el duelo serían realidades redefinidas y articuladas a través del paradigma médico. La medicalización de la muerte y el morir ha sido relacionada con una creciente confianza en la ciencia, racionalidad y progreso como capaces de aportar soluciones a los problemas humanos (Conrad, 2008). En consecuencia, la intervención médica con frecuencia tiene que ver con la prescripción de fármacos para tratar problemas que se manifiestan en ámbitos clínicos pero que, en realidad, no lo son (por ejemplo, alguien puede sentir tristeza ante la muerte de un ser querido sin por ello tener un problema médico (Parens, 2013)).

La muerte y el morir como hechos biográficos –no exclusivamente biológicos– están mediados por las culturas de personas situadas en contextos particulares y es, desde esa visión particular, que es posible reconocer en la voz de las personas que se encuentran al final de su vida un reflejo de los valores y coordenadas que definen los paradigmas de cada momento[3]. Es por eso que, en la experiencia vivida de numerosos pacientes, muchas de las expresiones utilizadas permiten reconocer estas representaciones sociales sobre el sufrimiento y el morir que, en parte, son fruto de este marco referencial.

Tal y como se ha presentado hasta ahora, el significado del sufrimiento y de la muerte humanos no puede ser neutro o aséptico sino que forma parte de la urdimbre biológica, racional, afectiva, ética y conductual tanto en su dimensión individual como social. Un exceso de dolor o sufrimiento puede generar emociones negativas (desesperanza o miedo) que lleven a la razón a querer erradicar este sentimiento a través de la acción (suicidio u otras acciones relativas a la muerte voluntaria como el solicitar la eutanasia o suicidio asistido). Sin embargo, es evidente que de la base orgánica y fisiológica de la que parcialmente está compuesto el sufrimiento (*physis*) a las consecuencias prácticas que pueden derivarse de éste (*ethos*), se despliega todo un abanico cultural y social que permite modular distintas respuestas posibles generadas

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[3] En este punto puede advertirse que algunos sociólgos defienden que la experiencia no se *modula* culturalmente sino que se *construye* culturalmente.

por el cambio de las mentalidades, actitudes y manifestaciones, en este caso, en torno a la muerte, sufrimiento y sentido de la vida[4].

Esta tesis está dividida en dos partes. En la primera parte se tratarán de identificar algunas coordenadas clínicas, antropológicas y filosóficas del DAM. De forma específica, se introducirán las nociones de dignidad y de autonomía como factores que han sido relacionados con el DAM y la fenomenología de la enfermedad y de la corporalidad como marco para comprender la experiencia vivida de los pacientes que se encuentran en estas circunstancias. Asimismo, se presentarán algunas bases para aproximarse a la muerte y al deseo de morir desde una mirada filosófica y se tratarán de describir algunas coordenadas contextuales que permitan entender, desde la historia de las mentalidades, la génesis de algunos de los presupuestos que se han extendido en el contexto de final de vida. El objetivo de esta primera parte es enmarcar, contextualizar y señalar los grandes ejes desarrollados posteriormente en los artículos. Asimismo, cuando sea oportuno se justificarán las preguntas de investigación u objetivos de esta tesis[5].

En la segunda parte, se presentarán los artículos que constituyen la parte esencial de esta tesis, junto con las preguntas de investigación, objetivos, metodología, discusión, implicaciones para la práctica, líneas de investigación y conclusiones.

El punto de partida de esta tesis se encuentra en los resultados obtenidos en el seno de las investigaciones llevadas a cabo por la Cátedra WeCare: Atención al final de la vida[6]. En el año 2011, la Dra. Cristina Monforte presentó su tesis doctoral que tenía por título ‘El deseo de adelantar la muerte en pacientes con procesos avanzados de enfermedad’. En esta tesis, el tema de la dignidad apareció como un factor relacionado con la emergencia del deseo de adelantar la muerte desde la perspetiva de los propios pacientes. Sin

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[4] “Hacer del dolor un simple dato biológico es insuficiente en la medida en que su humanización es la condición necesaria para que se presente a la consciencia, y porque entre una realidad espacio-temporal y otra, los hombres no sufren del mismo modo ni en el mismo momento” (Le Breton, 1999, p. 138).

[5] En el punto Capítulo 8 del compendio se desarrollan de forma más extensa y concreta las preguntas de investigación y objetivos generales y específicos de esta tesis.

[6] Para más información sobre la Cátedra WeCare puede consultarse: www.wecare.uic.es/inicio/

embargo, no era claro qué significado tenía para los pacientes la expresión de la “pérdida de dignidad”, ni en qué se fundamentaba el deseo de autodeterminación de algunos de los pacientes en relación con la dignidad y su propia identidad. Es por eso que en una primera etapa de la presente tesis se ahondó en la revisión de la literatura biomédica que giraba en torno al concepto de dignidad en el contexto de final de vida y en una segunda etapa sobre el concepto de autonomía, control y autodeterminación en esta misma población. Finalmente, se identificó que en la literatura científica faltaba una revisión más exhaustiva y síntesis de estudios sobre la relación entre dignidad y autonomía en la experiencia de los propios pacientes. De este modo, bajo el marco del deseo de adelantar la muerte, se ha profundizado en el concepto de dignidad y autonomía en el contexto de final de vida. De forma paralela, aunque en la tesis se presente como un resultado posterior, se ha llevado a cabo un análisis filosófico que ha permitido observar este fenómeno a través de una mirada antropológica.

Por último, podría decirse que los capítulos 2-5 y 6-7, aunque planteen temas comunes, podrían distinguirse como secciones diferentes en tanto que la perspectiva y el lenguaje utilizados son distintos. A pesar de esto, el hecho de haber tratado las nociones de deseo de adelantar la muerte, dignidad o autonomía desde una perspectiva empírica facilita que en el desarrollo ulterior –filosófico-antropológico– puedan asumirse con mayor riqueza estos conceptos y se pueda profundizar en ellos considerando su complejidad.

Primera parte:

De la investigación empírica, a la reflexión filosófica

Capítulo 2. El deseo de adelantar la muerte en pacientes al final de la vida

En el contexto de enfermedades avanzadas, no es infrecuente que algunos pacientes expresen un cierto deseo de adelantar la muerte (Bellido-Pérez et al., 2017). En una reciente revisión sistemática sobre instrumentos clínicos que evalúan el DAM se ha señalado que, en este ámbito, el DAM podría tener una prevalencia de entre el 1,5 al 37,8% (Bellido-Pérez et al., 2017). Este amplio rango obedece, principalmente, a la naturaleza de las muestras de pacientes estudiadas, a la falta de precisión conceptual del concepto evaluado y a los diferentes instrumentos de evaluación utilizados; todos ellos aspectos que limitan la comparación de los resultados. A pesar de las dificultades halladas, se han llevado a cabo diversos estudios para comprender cuál es la naturaleza del DAM, cuáles son los factores asociados (físicos, psicológicos, sociales y existenciales/espirituales) (Albert et al., 2005; Monforte-Royo et al., 2011, Monforte-Royo, Porta-Sales y Balaguer 2016; Villavicencio-Chávez et al., 2014), qué implicaciones éticas y legales puede tener (Materstvedt, 2015; Ohnsorge et al., 2012) y cuáles son las razones, significados e intenciones de las personas que expresan este deseo de morir (Coyle y Sculco, 2004; Nissim, Gagliese y Rodin, 2009; Ohnsorge, Gudat y Rehmann-Sutter, 2014a; Ohnsorge, Gudat y Rehman-Sutter, 2014b; Pearlman et al., 2005).

En la línea de comprender los factores que contribuyen a la aparición del deseo de adelantar la muerte, estudios cuantitativos han tratado de identificar los siguientes aspectos etiológicos o factores relacionados: el malestar general, el dolor, la disnea, la incapacidad de realizar actividades placenteras, el ser dependiente, el ser una carga para los demás, la pérdida del sentido de la vida, la preocupación por un sufrimiento futuro, el deseo de control sobre el momento de la muerte, la pérdida de autonomía, la pérdida del sentido de la dignidad, etc. (Guerrero-Torrelles et al., 2017; Robinson et al. 2017; Rodin et al., 2007; Villavicencio-Chávez et al., 2014). En algunos estudios, también se ha visto que la depresión o la desesperanza son factores precursores o antecedentes del DAM. Por ejemplo, en un estudio llevado a cabo por Breitbart et al. (2000) se observó que en los pacientes que presentaban deseo de morir, era cuatro veces más probable que estuvieran deprimidos frente a los que no y en otro de Akecthi et al. (2001) se vio que de su muestra de 1721 pacientes, 220 fueron diagnosticados con depresión mayor y de entre estos el 51,4% tuvo ideación suicida. Con todo, la evidencia clínica apunta a que el DAM es un fenómeno multidimensional y, por lo tanto, no reductible a factores aislados.

Hasta el momento se ha utilizado el DAM para referir diferentes conceptos. Por ejemplo, algunos autores lo utilizan para referirse a pensamientos genéricos o vagos en torno a la muerte; otros para describir la intención de finalizar con la vida y con las peticiones explícitas de eutanasia y suicidio médicamente asistido. En cualquier caso, muchas veces se han utilizado estas expresiones como sinónimos, aspecto que resalta su naturaleza subjetiva y las formas diferentes en que puede ser interpretado. En algunos países, el creciente debate sobre la eutanasia o el suicidio asistido no ha hecho más que aumentar esta posible confusión entre un ‘deseo de morir pero sin considerar adelantar la muerte a través de la acción’ respecto a ‘actuar con la intención de quitarse la vida (a través del suicidio o suicidio asistido)’ (Ohnsorge, Gudat y Rehmann-Sutter, 2014a).

Dada la confusión terminológica y conceptual, un grupo de expertos internacionales en el ámbito (Balaguer et al., 2016, p. 8), liderado por nuestro equipo, consensuó una definición operativa del DAM[7] como una “reacción al sufrimiento, en el contexto de una enfermedad que amenaza la vida” en que el paciente no atisba otra salida que la de acelerar su muerte. Este deseo puede expresarse de forma espontánea o tras ser preguntado, pero debe distinguirse de la aceptación de una muerte inminente o el deseo de morir que puede surgir de forma natural, aunque preferiblemente pronto[8]. En este sentido, atender y

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[7] Los objetivos de este trabajo fueron consensuar una definición operativa del DAM en el contexto-situación de pacientes con enfermedades que amenazan su vida; así como unificar las expresiones que hacen referencia al DAM. De esta forma, se pretendió delimitar el fenómeno del DAM a una situación clínica particular y proponer a los profesionales de la salud una terminología para evitar esta equivocidad terminológica. La expresión deseo de adelantar la muerte (DAM) es la traducción literal de *wish to hasten death* (*WTHD)*, término consensuado.

[8] La definición que se consensuó a nivel internacional incluye no solo la precisión conceptual y terminológica del uso de la expresión del deseo de adelantar la muerte, sino también de sus factores relacionados. A continuación se expone la definición y factores relacionados tal y como se consensuaron: “*The wish to hasten death (WTHD) is a reaction to suffering, in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate his or her death. This wish may be expressed spontaneously or after being asked about it, but it*

comprender la naturaleza del sufrimiento, conocer la biografía, actitudes, creencias, pensamientos desde el punto de vista de los propios pacientes, es especialmente relevante en la práctica clínica puesto que de modo inevitable, este malestar, afecta a todas las dimensiones de la persona.

De esta forma podría definirse el deseo de morir como un deseo general que abarcaría distintos grados de intencionalidad –por ejemplo, desde la aceptación de la muerte a la petición de eutanasia–, y el DAM como un deseo que se daría en el contexto particular tal y como se ha definido (Balaguer et al., 2016). Según esta definición operativa, las vivencias fuera de este contexto de sufrimiento no implicarían necesariamente ser denominadas propiamente como DAM. Bajo este marco, tampoco todo deseo de morir racional, por ejemplo, por estar cansado de vivir, podría entenderse como tal, partiendo de la base de que el DAM se ha acuñado –en un sentido estricto– en el contexto de una enfermedad que amenaza la vida e implica sufrimiento.

Algunos autores también han observado que el DAM puede variar en frecuencia en el tiempo, a la vez que puede ser expresión de cierta ambivalencia por parte de los pacientes. Por ejemplo, Chochinov et al. (1995) observaron que el deseo de morir puede coexistir con un deseo de vivir y Ohnsorge, Gudat y Rehman-Sutter (2014a) que este deseo puede tener otras intenciones y significados en los pacientes que no necesariamente tengan que ver con que quieran morir, aunque ellos así lo verbalicen. De esta forma, podría decirse que el deseo de morir y el deseo de vivir pueden presentarse de forma intermitente, e incluso, paradójicamente, coexistiendo en algunos momentos o situaciones.

Un caso interesante que permite reflexionar acerca del deseo de morir es la interrupción voluntaria de la nutrición y de la alimentación (VSED[9]). Hasta

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must be distinguished from the acceptance of impending death or from a wish to die naturally, although preferably soon.
The WTHD may arise in response to one or more factors, including physical symptoms (either present or foreseen), psychological distress (e.g. depression, hopelessness, fears, etc.), existential suffering (e.g. loss of meaning in life), or social aspects (e.g. feeling that one is a burden)" (Balaguer et al., 2016, p.8).

[9] En adelante se utilizará este acrónimo para mencionar la interrupción voluntaria de la nutrición y de la alimentación siguiendo la expresión inglesa que está más extendida que la española: *voluntary stopping of eating and drinking.*

el momento, el VSED es un fenómeno bastante desconocido en la práctica clínica sobre el que no hay mucha evidencia empírica. Por ejemplo, en países como Holanda se ha estimado que entre un 1,4%–2,09% (que equivalen a 1700–3900 muertes/año) de personas murieron por VSED entre el año 1999 al 2003 (Ivanović, Büche y Fringer, 2014). Y en un estudio llevado a cabo en Oregón, se identificó que de las 307 enfermeras que participaron en el estudio, 102, en los últimos cuatro años habían cuidado a algún paciente que había muerto por VSED (Ganzini et al., 2003). Sin embargo, no hay evidencia sobre la prevalencia de las muertes por VSED más allá de las que se reportan en pocos estudios (Chabot y Goedhart, 2009; Ganzini et al., 2003; Ivanović et al., 2014).

Con todo, un dato en el que coinciden la mayoría de estudios publicados es sobre la urgencia de profundizar en las necesidades físicas, psico-emocionales, existenciales de los pacientes que se encuentran en estas circunstancias. Recientemente, Bolt et al. (2015) analizaron el rol e implicación de los médicos de familia al confrontarse con pacientes que deseaban morir a través del VSED. En este estudio se describe el VSED como la actitud de enfermos adultos o de ancianos que, sin deterioro cognitivo significativo, siendo capaces de ingerir alimentos e hidratarse, de forma consciente y voluntaria decidieron dejar de hacerlo. En este sentido, algunos autores han definido el VSED como una forma de suicidio –parecido al suicidio asistido– a través del cual se persigue acabar con un sufrimiento inaceptable o insoportable (Bolt et al., 2015). Por ejemplo, Thimothy Quill (2015) sostiente que, aunque el VSED y el suicido asistido son prácticas similares en muchos aspectos, el VSED parecería ofrecer a los pacientes un mayor control sobre el proceso de finalizar la vida (al no provocar la muerte inmediata, y ser, de algún modo, reversible) y permitiría mantener la independencia del paciente respecto a los profesionales de la salud, al no hacer necesaria su intervención.

Desde un punto de vista ético, el VSED plantea la cuestión acerca de qué acciones[10] deberían llevar a cabo los profesionales de la salud ante el paciente que voluntariamente deja de alimentarse con el fin de morir y en qué

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[10] Aquí la palabra acción quiere contraponerse a omisión.

medida los profesionales tienen el deber de entrometerse en la decisión de alguien que libremente desea la muerte.

El VSED como desafío ético, a la luz de la evidencia clínica sobre el DAM (Monforte-Royo et al., 2011, 2012), pone de relieve la necesidad de, en primer lugar, entender qué subyace detrás de este fenómeno complejo. Si la ética se pregunta por las acciones libres del ser humano, por aquello que es capaz de hacer u omitir, por el modo en que puede alcanzarse el bien de las personas (en este caso pacientes con enfermedades avanzadas) se hace patente que la actuación de los profesionales ante tales casos difícilmente pueda ser neutra.

Los estudios cualitativos publicados sobre el DAM han ayudado a profundizar sobre el significado que los pacientes atribuyen al DAM cuando lo expresan. Hasta el año 2010, siete artículos habían sido publicados en Australia (Kelly et al., 2002), Canadá (Lavery et al., 2001; Nissim et al., 2009), China (Mak y Elwyn, 2005) y Estados Unidos (Coyle y Sculco, 2004; Pearlman et al., 2005; Schroepfer, 2006). Desde entonces siete artículos más han sido publicados también en países europeos (Alemania (Pestinger et al., 2015; Stiel et al., 2010), Holanda (Dees et al., 2011) y Suiza (Ohnsorge et al., 2012; Ohnsorge, Gudat y Rehmann-Sutter, 2014a, 2014b), además de otro publicado en Tailandia (Nilmanat et al., 2015). Estos estudios que en total suman una muestra de 255 pacientes (280 participantes si se cuentan los familiares y profesionales del estudio de Pearlman et al. (2005)) suponen una base valiosa para entender la experiencia de las personas que manifiestan DAM.

A la luz de esta mirada cualitativa, puede identificarse que el significado que los pacientes atribuyen al DAM no solo puede ser visto como un deseo ‘auténtico’ o ‘genuino’ de morir sino también como una experiencia estrechamente ligada al sufrimiento físico, psico-emocional, social e incluso espiritual-existencial, asociado a funciones e intenciones[11].

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[11] Numerosos estudios han destacado la complejidad de la expresión del DAM más allá de las variables clínicas con las que se ha relacionado (p.e depresión, desesperanza, etc.) (Akechi et al., 2001; Breitbart et al., 2000; Chochinov et al., 1995; Robinson et al., 2017; Rodin et al., 2009).

El afrontamiento del DAM atendiendo a su origen multifactorial puede ser crucial a la hora de distinguirlo de la simple petición de eutanasia o suicidio asistido. En consecuencia, profundizar en los valores y actitudes por las cuales los pacientes expresan conscientemente o no el DAM así como ahondar en sus significados puede ser clave para poder desarrollar planes de cuidado adecuados a las necesidades reales de los pacientes. En este sentido, algunos factores asociados al DAM –vinculados a los significados atribuidos por los pacientes– son especialmente controvertidos y difíciles de definir sin acudir a una mirada filosófica que reconozca los sustratos morales y socio-culturales en la voz de los pacientes. Por ejemplo, la pérdida de percepción de dignidad puede ser uno de los factores predictores del DAM; sin embargo, dignidad frecuentemente es utilizada en la literatura de forma ambigua, es objeto de discusión y da lugar a opiniones contrapuestas. Esto mismo ocurre con el uso del término autonomía que, en este contexto de DAM, puede ser utilizado tanto como pérdida de control sobre las funciones físicas, como deseo de control sobre el proceso de final de vida (decidir cómo y cuándo morir) e incluso puede ser vista como el fundamento de la dignidad[12].

En consecuencia, ahondar sobre cómo se entienden dignidad y autonomía y qué relación existe entre ambas en la experiencia de los pacientes al final de vida resulta crucial para superar los interrogantes que surgen ante esta falta de claridad conceptual en la literatura. De hecho, dependiendo del estatus normativo que se le asigne tanto a dignidad como autonomía se podrán dar respuestas distintas ante preguntas relevantes: ¿Qué vínculo hay entre autonomía y dignidad? ¿Es la autonomía su fundamento? ¿Siguen manteniendo su dignidad las personas dependientes? ¿La pérdida de funcionalidad física y control puede contribuir una pérdida de sentido de la vida? ¿Morir con dignidad significa decidir cómo y cuándo morir?

Dando un paso más, tal y como afirma Ohnsorge (2015), el debate sobre algunas cuestiones bioéticas con frecuencia se ha dado contraponiendo principios fundamentales. Por ejemplo, tal y como se ha dicho, en el discurso sobre la eutanasia es común la alusión a la defensa de la autonomía,

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[12] En los apartados siguientes se desarrollará con mayor profundidad cómo se entienden ‘dignidad y autonomía en la literatura científica en el contexto de final de vida’.

autodeterminación y dignidad; y, paradójicamente es frecuente que se utilicen estos principios para defender posiciones contrarias. En estos casos, puede entenderse esta divergencia –sigue apuntando Ohnsorge– no como un “desacuerdo moral” sino como un conflicto interpretativo[13] generado por las distintas formas de entender el mundo.

En efecto, tanto dignidad como autonomía refieren al sistema de valores y creencias de los pacientes generados dentro de micro y macro contextos. Por micro-contexto puede entenderse todo aquello de la biografía junto con las actitudes, creencias y pensamientos de la persona que marca su personalidad, su manera de ver y vivir la vida y por macro-contexto el marco cultural, legal, social, histórico que igualmente influye en cómo la persona entiende el mundo y construye significados a través de su experiencia.

Por eso, profundizar sobre cómo perciben su dignidad y autonomía los pacientes al final de la vida, cómo expresan tales percepciones, y cómo son entendidas por sus interlocutores (familiares, profesionales) es uno de los objetivos de esta tesis (primer artículo).

Asimismo, la existencia de nuevos estudios llevados a cabo en contextos europeos permite cuestionarse ¿Por qué algunos pacientes con enfermedades avanzadas desean adelantar su muerte? ¿Qué significa para ellos ese deseo? ¿Cuál es la vivencia de la persona que lo experimenta? ¿Hasta qué punto hay aspectos comunes en los que lo sienten?

En consecuencia, otro de los objetivos de esta tesis y el tercero de los artículos presentados fue actualizar el conocimiento del DAM –a la luz de los estudios cualitativos publicados– en base a una representación más amplia en términos de diversidad ético-cultural y conocer si esta diversidad influye de algún modo en el DAM expresado. El análisis de las citas extraídas de los estudios cualitativos sobre el DAM permite identificar algunas afirmaciones que reflejan presupuestos sobre el valor de la persona y el valor de la vida bajo la

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[13] Para un autor tan representativo como Alasdair MacIntyre, este tipo de conflicto interpretativo no tiene posible solución. Basta leer el capítulo introductorio o prólogo de *Tras la virtud* (2001). En consecuencia, sólo puede optarse por una u otra tradición y vivir en ella de la manera más honesta posible. Agradezco este comentario al Dr. Xavier Escribano.

caracterización de un marco referencial que encaja bien con lo que se ha definido como medicalización. Por eso, otro objetivo de esta tesis fue analizar esta mirada atributiva, que presupone valores morales y creencias, que es capaz de reconocer, ratificar, desacreditar o reforzar la identidad y percepción de la dignidad de los pacientes (cuarto artículo) a la luz de las expresiones verbales extraídos de los estudios cualitativos sobre el DAM. Entender estos valores puede ser igualmente crucial a la hora de entender la vivencia de quien expresa cierto deseo de adelantar la muerte.

Finalmente, el deseo de morir entendido como un deseo general que abarcaría distintos grados de intencionalidad –por ejemplo desde la aceptación de la muerte a la petición de eutanasia o a la muerte por VSED– conecta con el dilema ético ya planteado acerca de las acciones (u omisiones) que deben llevar a cabo (o no) los profesionales de la salud. Así pues, los últimos objetivos de esta investigación fueron comparar el fenómeno de VSED a la luz de los resultados de los estudios cualitativos sobre el DAM y analizar si el VSED puede considerarse como una expresión concreta del DAM (quinto artículo).

En el siguiente capítulo, se abordará el concepto de la dignidad en el ámbito de la literatura biomédica, teniendo en cuenta que es uno de los antecedentes del DAM en los pacientes que se encuentran al final de su vida.

Capítulo 3. La dignidad en la literatura biomédica en el contexto de final de vida

3.1 Breve historia del binomio dignidad-autonomía en el contexto del final de vida

A partir de los años 60 el abuso cometido hacia algunos grupos vulnerables de la sociedad (personas enfermas o con alguna discapacidad, personas ancianas o niños), la atención precaria recibida por los pacientes que no presentaban esperanza de curación, el recuerdo de los experimentos con humanos realizados en los campos de concentración nazis; junto a la emergencia de algunos casos extremos que cuestionaban el límite de la intervención médica, despertó la necesidad de establecer una ciencia ética y clínica que protegiera a las personas en el contexto sanitario. A esta ciencia nueva se le llamó bioética (Potter, 1971).

En 1962 un grupo de no-profesionales –el llamado '*God Commitee'* de Seattle– recibió el cometido de seleccionar a pacientes que potencialmente podían ser sometidos a tratamiento sustitutivo renal con hemodiálisis. La falta de conocimiento en la materia y la aplicación de unos criterios arbitrarios hizo que el '*God Commitee'* se conviertiera en un escándalo nacional e hizo detener su actividad. En 1963 salió a la luz que a 19 ancianos del Jewish Chronic Disease Hospital (Brooklyn), sin previo consentimiento, les habían inyectado células cancerígenas para comprobar si su cuerpo las rechazaba. De 1965 a 1971, niños discapacitados y hospitalizados en el Willowbrook State Hospital (Nueva York) fueron inyectados con el virus de la hepatitis sin su consentimiento ni el de sus padres. En 1968 el Dr. Henry Beecher publicó datos relativos al experimento de Tuskegee, un estudio longitudinal (1930-1972) en el que habían participado más de 400 hombres de raza negra a los cuales se les había inyectado la bacteria de la sífilis (*Treponema Pallidum*). El objetivo de este estudio fue observar el desarrollo natural de la sífilis cuando no es tratada (recuérdese que la comercialización de la penicilina –tratamiento que se había demostrado eficaz en contra de la sífilis– data de principios de la década de 1940). En el año 1976 se tomó la decisión de que a Karen Ann Quinlan, una mujer con una anoxia prolongada, se le retirara la ventilación artificial tras un año en estado de coma. Su caso abrió el debate sobre la limitación del esfuerzo terapéutico en el contexto de progreso tecnológico actual.

En esta misma época, revistas científicas como *New England Medical Journal* y *The Lancet*, dos de las revistas más prestigiosas en el ámbito clínico posicionadas en primer y segundo lugar teniendo en cuenta su factor de impacto, empezaron a publicar artículos que debatían sobre la eutanasia, el derecho a morir con dignidad y el cuidado que merecen las personas en situaciones de final de vida (Clark, 2002). Hasta entonces, los pacientes con cáncer habían sido centro de la atención médica cuando era esperable su curación. Sin embargo, junto al desarrollo de una incipiente filosofía de los cuidados paliativos[14], la atención empezó a focalizarse no solo en los aspectos curativos, sino también en los aspectos de cuidado y acompañamiento que tenían el presupuesto de que la vida es valiosa, merece y puede ser vivida hasta el final. Esta nueva aproximación hacia las personas con enfermedades avanzadas tuvo que ver con la consideración de los factores psicológicos, sociales, existenciales o espirituales como claves del bienestar de los pacientes. De este modo, el lema de “ya no hay nada más que hacer” fue substituido por la conciencia de “curar a veces, aliviar a menudo, consolar siempre” y con la consideración de que los aspectos vivenciales de la enfermedad, la impronta que genera en la biografía del paciente son elementos cruciales a tener en cuenta (Casell, 1982).

El concepto de dignidad, en este contexto ayudó a centrar la idea de que la persona es *alguien* que posee un valor irrenunciable e inviolable a pesar del proceso penoso que pueda vivirse en la enfermedad. El desarrollo de un cuidado que atiende a la dignidad de la persona, precisamente, tiene que ver con la consideración de que la persona es siempre un fin y un bien en sí

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[14] La filosofía de los cuidados paliativos, impulsada por Cicely Saunders (1965), contribuyó a la promoción de un cuidado que integrara y relacionara todas las dimensiones de la persona saliendo al paso de la extendida idea de que nada más puede hacerse con el enfermo terminal que se encuentra en sus últimos momentos de vida. A la inefectividad del tratamiento curativo le puede proseguir un tratamiento paliativo que atienda tanto al control de síntomas como a la depresión, miedo ante un futuro incierto, angustia, pérdida de sentido de la vida, pérdida del sentido de dignidad, etc.

mismo, alguien que merece toda la atención y respeto de los profesionales de la salud hasta el final de sus días (Saunders, 1965)[15].

Sin embargo, la noción de dignidad rápidamente fue equiparada a la de autonomía. La posibilidad de encarnizar terapéuticamente a los pacientes y no tener un criterio claro sobre los límites de la intervención médica, el manejo inadecuado del dolor y de los síntomas, el hecho de vivir con un sufrimiento 'insoportable', las condiciones penosas en las que algunos pacientes con enfermedades avanzadas mueren, y la presencia de casos límite que reclaman el derecho a que se pueda determinar la propia muerte para evitar estas circunstancias 'indignas' de la persona (como lo serían el dolor, la pérdida de funcionalidad física, de autonomía, la incapacidad de disfrutar de las actividades de la vida ordinaria, etc.) bajo el amparo de la ley, generó en diversos países el surgimiento de movimientos a favor de la 'Muerte con dignidad' (Hendin, 2009; Montero, 2013). La idea de morir con dignidad –que se desarrollará en el apartado 5.1– presupone que la persona no posee una dignidad intrínseca puesto que el valor de la persona puede depender de las circunstancias en las que vive. Asimismo, presupone que la dignidad se fundamenta en la autonomía y que la capacidad de establecer la propia ley, el poder autodeterminar la propia vida de acuerdo a los valores y deseos personales es lo que define la propia dignidad.

Desde el punto de vista de la historia de las ideas, no es nueva la interrelación de estos dos conceptos. Pico della Mirandola (2003) en su conocido discurso sobre la dignidad del hombre, precisamente destacó que lo que hace que el ser humano sea un ser único es la capacidad humana para configurar su vida.

Las tesis kantianas se consideran fundantes del discurso moral moderno sobre la dignidad (Shell, 2008). En primer lugar, Kant define dignidad como "aquello que constituye la condición para que algo sea fin un sí mismo" (Kant,

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[15] No hay que olvidar que los cuidados paliativos fueron promovidos bajo una idea cristiana de la persona y del enfermo (Coward y Stajduhar, 2012). La idea cristiana del cuidado por un lado, considera la dignidad intrínseca del ser humano como realidad inseparable de la imagen de Dios que hay en cada individuo. Y por otro, considera que en cada persona sufriente está el mismo Cristo paciente (Juan Pablo II, 1984).

2002, p. 2, Abs. (III 60)), no relativo a un valor contingente o a un precio (objeto de evaluación condicional) como sostuvo Hobbes (1914)[16]. Este principio encuentra su consecuencia práctica en el imperativo de tratar al otro (a la humanidad) y a uno mismo como tal; y en él encuentra su fundamento la moral. En segundo lugar, la dignidad sería una condición de la persona en virtud de su naturaleza racional a partir de la cual cobra sentido el concepto de autonomía. Para Kant, autonomía tiene que ver con la responsabilidad de actuar de acuerdo con la ley-deber moral guiada por la razón.

La recepción del concepto kantiano de dignidad, a menudo, aúna la idea de dignidad entendida como la condición intríseca que da valor a la persona y dignidad entendida como capacidad del agente moral que puede decidir de forma autónoma, conviertiéndose en ley para sí. Así, por ejemplo, Goodin (1981, pp. 91–95 citado en Pullman, 1996, p.199) afirma que "el hombre se dirige hacia una existencia dignificada y merecedora [digna] de respeto moral, exclusivamente y en tanto que, se convierte en auto-legislador [de su propia vida], vence la natural necesidad y está dispuesto a [responsabilizarse de] sus propias acciones". En esta última definición, a diferencia del planteamiento de Kant, el sujeto auto-legislador no busca obedecer a una ley que pueda ser válida de forma universal sino que la auto-configuración moral estará determinada por lo que le dicte su propia conciencia asumiendo que el juicio que emita será subjetivo y no deberá imponerse como norma para los demás[17].

Desde la óptica clínica, la identificación de la dignidad con la autonomía puede enmarcarse en el auge del modelo principialista anglosajón que defiende que, precisamente el principio de autonomía, debe ser el pilar que fundamente los protocolos de bioética. Como consecuencia de los abusos cometidos a personas que fueron intervenidas sin consentimiento, etc. se empezó a destacar la necesidad de respetar a los pacientes en sus "convicciones éticas", reconociéndolos como agentes autónomos (Davis, 2008, p. 24).

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[16] "Y como en otras cosas, así en cuanto a los hombres, no es el vendedor, sino el comprador quien determina el precio. Porque aunque un hombre (cosa frecuente) se estime a sí mismo con el mayor valor que le es posible, su valor verdadero no es otro que el estimado por los demás" (Hobbes, 1914. Capítulo X, 16).

[17] Charles Taylor en *Sources of the self* (1992), desarrolla de forma magistral y exhaustiva el origen de este yo moderno.

Por el contrario –o *mutatis mutandi* de forma complementaria–, el legado de la bioética europea aporta una visión distinta, precisamente porque resalta la centralidad del concepto de la dignidad en el marco de toma de decisiones clínicas y defiende que no puede ser reductible al concepto de autonomía (Rendtorff, 2002). En el *Final Report on the Project Basic ethical principles in European bioethics and biolaw*, se identificó la dignidad, junto a la autonomía, integridad y vulnerabilidad como marco para proteger a la persona de un desarrollo tecnológico deshumanizado. Tras examinar y discutir qué significa el concepto de dignidad se definió como "una cualidad de la persona como tal. [La dignidad] actualmente se refiere a tanto el valor intrínseco de una persona como al valor intersubjectivo de cada ser humano en su encuentro con el otro […] La dignidad tiene que ver con uno mismo y con el otro: yo debo actuar con dignidad y debo tener en cuenta la dignidad del otro" (Rendtorff, 2002). Esta definición, puede servir como marco para diseñar guías para la práctica clínica, salvaguardando el valor inherente de la persona humana y protegiéndola de las concepciones que entienden que las personas, en estas circunstancias, ya no tienen valor. En un plano normativo puede ser difícil acordar cuáles son las consecuencias de afirmar que existe una dignidad intrínseca –baste considerar la imprecisa definición de dignidad intrínseca tal y como es presentada por la Declaración de los Derechos humanos (Organización de las Naciones Unidas, 1948)–, pero reconocer a otro ser humano como ser humano es necesario para respetar a la persona y protegerla de cualquier reduccionismo en el que se pueda caer, especialmente en estados avanzados de enfermedad donde la vulnerabilidad del ser humano se hace patente.

3.2 La dignidad en la literatura biomédica en el contexto de final de vida

> "¿La dignidad humana –es un concepto útil en bioética, que proyecta luz sobre el amplio espectro de temas bioéticos, como la investigación con embriones y la reproducción asistida, el desarrollo biomédico o el cuidado de las personas con discapacidad y las que se encuentran al final de la vida? ¿O es, por el contrario, un concepto inútil– en el mejor de los casos un vago sustituto de otros conceptos, y en el peor, un mero eslogan que camufla argumentos que no convencen y sesgos inarticulados?" (Schulman, 2008, p. 3).

En el año 2003 Ruth Macklin publicó su polémico artículo '*Dignity is a useless concept*' ['La dignidad es un concepto inútil'] (Macklin, 2003) a través del cual defendía que la noción de dignidad podía eliminarse del discurso ético sin miedo a perder ningún contenido valioso. Desde entonces, algunas voces se han posicionado a favor y en contra del eslogan planteado por Macklin. Precisamente, Adam Schulman, en la cita recogida arriba, encabezó el informe comisionado por el *President's Council on Bioethics* sobre la 'Dignidad humana y bioética' retomando la pregunta acerca de la utilidad de la dignidad en el discurso bioético.

Algunos abusos cometidos a lo largo del siglo XX (experimentación humana, encarnizamiento terapéutico) han dado pie a que distintas declaraciones[18] hayan intentado normativizar el concepto de dignidad. Sin embargo, la multiplicidad de puntos de vista (ontológico, utilitarista, feminista, personalista, etc.) a través de los cuales, se reflexiona sobre este concepto, dificulta el consenso sobre su significado y reconocer hasta qué punto puede ser útil.

Parte de la falta de consenso sobre qué significa dignidad, sin duda, tiene que ver con las múltiples disciplinas desde las que se aborda el término[19].

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[18] Por ejemplo, la Declaración Universal de los Derechos Humanos (1948), la Declaración de Helsinki (1964), la Declaración de Alma Ata (1978), la Declaración Universal sobre el Genoma humano (1997), etc. También se llevaron a cabo diversos Proyectos de investigación para proteger a poblaciones vulnerables, como la *Research Involving the Fetus* (1975), *Research Involving Prisoners* (1976), *Research Involving Children* (1977), *Psychosurgery: Report and Recommendations* (1977), *Disclosure of Research Information under the Freedom of Information Act* (1977), *Research Involving Those Institutionalized as Mentally Infirm* (1978). Para una información más detallada ver Daniel F. Davis (2008).

[19] Por ejemplo, desde la filosofía, desde las ciencias empíricas, jurídicas, etc.

La noción de dignidad, desde la perspectiva filosófica, con frecuencia se ha tratado como un concepto abstracto y universalista (cfr Macklin, 2003). Es decir, como un concepto que se aplicaría de forma general, sin atender a las particularidades de cada situación específica. Por el contrario, desde una perspectiva empírica parece concebirse de un modo particularista, relativo a las circunstancias y valores de cada persona. Del mismo modo, la defensa del derecho a morir bajo el eslogan de "dignidad" no hace más que dificultar la comprensión de este término. Como consecuencia de esta falta de claridad terminológica, en el apartado siguiente tratarán de describirse algunos escenarios (contextos) y sentidos (significados) de dignidad en la literatura biomédica[20].

3.3 Los escenarios y sentidos de dignidad en la literatura científica en el contexto de final de vida

En la literatura biomédica se podrían distinguir tres escenarios o ámbitos en los que se utiliza el concepto de dignidad al final de la vida: dignidad como cualidad de la persona (en relación con la percepción de identidad tanto desde el punto de vista de los pacientes como de los profesionales de salud y entorno social inmediato) (Bayer, Tadd y Krajcik, 2005; Chochinov et al., 2002; Enes, 2003; Franklin et al., 2006; Jacelon, 2003; Li, Richardson, Speck y Armes, 2014; Pleschberger, 2007); pérdida del sentido de dignidad como mediadora del deseo de adelantar la muerte (Monforte-Royo et al., 2012; Pearlman et al., 2005; Vehling y Mehnert, 2014); y como argumento estratégico de movimientos a favor de la eutanasia y del suicidio asistido bajo la expresión 'muerte digna' (Batavia, 2000; Chin et al., 1999; Hendin, Foley y White, 1998; Miller, 2000; Sampaio, 1992; Sullivan, Hedberg y Hopkins, 2001).

Existen algunas revisiones narrativas (Haddock, 1996; Street y Kissane, 2001) y sistemáticas (Guo y Jacelon, 2014; Östlund, Brown y Johnston, 2012) sobre dignidad al final de la vida. Del mismo modo, numerosos autores han profundizado sobre su significado desde un punto de vista teórico (Johnson, 1998; Pullman, 1996; Sulmasy, 2005) y se han planteado qué significa la

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[20] En este apartado es preciso distinguir entre los escenarios en los que aparece dignidad, de los sentidos de dignidad. Si bien es verdad que se entrelazan, es distinto hablar de los contextos en los que aparecen que hablar de cómo se entiende dignidad en cada uno de ellos.

‘muerte con dignidad’ (Abiven, 1990; Cooper, 1997; Guo y Jacelon, 2014; Pullman, 2004; Sampaio, 1992; Toombs, 2004). A pesar de esto, son frecuentes las alusiones a su equivocidad y a la carencia de una definición común. Partiendo de esta falta de consenso mencionada en la literatura, Chochinov et al. (2002) fueron los primeros en plantear un estudio cualitativo que explorase el sentido de dignidad bajo la perspectiva de los propios pacientes. Hasta entonces, numerosos profesionales de la salud habían insistido en la importancia de reconocer la dignidad como una cualidad inherente del ser humano. Sin embargo, tal y como apuntan Chochinov et al. (2002) era necesario definir de forma operativa qué significa dignidad para poder concretar en la práctica clínica una atención que respondiera a cómo los pacientes perciben su propia dignidad. En otras palabras podría decirse que una de las grandes aportaciones del estudio de Chochinov et al. (2002), radica en el hecho de conectar este ideal filosófico de dignidad con el contexto clínico en el que se encuentran los pacientes. Considerar el punto de vista de los pacientes, sus experiencias, su voz en primera persona se ha visto como un testimonio valioso que permite comprenderlos y atenderlos de una forma más adecuada teniendo en cuenta sus necesidades reales.

Desde entonces, se han llevado a cabo numerosos estudios ahondando en esta percepción desde el punto de vista de pacientes con enfermedades avanzadas (Brown et al., 2011; Chochinov, 2002; Enes, 2003; Ho et al., 2013; Ho et al., 2013) y ancianos (Bayer et al., 2005; Franklin et al., 2006; Jacelon, 2003; Pleschberger, 2007); estudios transversales para detectar factores relacionados con la percepción de dignidad (Chochinov et al., 2002; Hack et al., 2004); e intervenciones para evaluar su sentido y mejorar su percepción (Chochinov et al., 2008; Hall et al., 2009; Periyakoil, Stevens, y Kraemer, 2013). En esta línea, además del de Chochinov, se han diseñado algunos modelos de dignidad para favorecer su cuidado y protección (Martínez et al., 2016; Östlund et al., 2012; Pleschberger, 2007; Vladeck y Westphal, 2012).

Asimismo, el reconocimiento del sufrimiento extremo, la falta de control sobre el dolor y el malestar emocional que, con frecuencia, suponen los procesos terminales de enfermedad −que para algunas personas es experienciado como una pérdida de sentido dignidad−, se han visto como factores que podrían mediar la emergencia del DAM.

Partiendo de este marco, numerosas organizaciones de distintos países del mundo[21] están impulsando la defensa a favor del derecho a morir a través de la despenalización del suicidio asistido y de la eutanasia (“Death with dignity,” 1982; Miller, 2000; Sampaio, 1992). Tanto investigadores como pacientes han afirmado que, en estas circunstancias, la muerte sería preferible a la enfermedad y que este proceso final de deterioro y sufrimiento no sería “digno” de la persona (Batavia, 2000; “Death with dignity,” 1982; Quill, 1991; Sampaio, 1992). Bajo este presupuesto, en distintos lugares del mundo el programa que aboga por la implementación y legalización de estas prácticas se ha denominado ‘muerte con dignidad’ (Van Brussel, 2014).

3.3.1 Los sentidos de dignidad

Los diferentes discursos en los que se ha reflexionado sobre la dignidad pueden llevar a dudar sobre si es posible y útil hablar de este concepto. Aschroft (2005) resolvió la cuestión aduciendo que “hablar de dignidad no es nada más que entender las formas en que se utiliza en el lenguaje ordinario” (p. 680); mientras que Singer y Kuhse (2003) y Macklin (2003) han afirmado que “la dignidad es un concepto inútil” porque es un concepto vacío que no aporta más significado que el que ya lo hacen, por ejemplo, las nociones de autonomía o de respeto. Sin duda, hay parte de razón en estas consideraciones pero el problema del relativismo lingüístico es nuclear. En la medida en que las palabras solo tienen sentido en el uso se hace difícil llegar a su significado.

Haddock en ‘*Towards further clarification of the concept 'dignity''* [‘Hacia una mayor clarificación del concepto de ‘dignidad’’] (1996) planteó de una forma interesante cómo comprender este concepto a la luz de la interacción entre a) lo que significa en sí y b) los pensamientos y valores asociados a su

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[21] Por citar algunos ejemplos: la ‘*vzw Recht op Waardig sterven’* y la ‘*Association pour le droit de mourir dans la dignite’’* en Bélgica, ‘*Dignitas’* o ‘*Exit’* en Suiza, la ‘*Dying with dignity*’ en Canadá y Estados Unidos, ‘Derecho a Morir Dignamente’ en España y la sociedad japonesa a favor de la muerte con dignidad.

percepción. Partiendo de esta distinción propuesta por Haddock se tratarán de describir los tres niveles de dignidad que se suelen mencionar en la literatura: dignidad en sentido intrínseco (referida al ser humano como cualidad o propiedad intrínseca), dignidad como cualidad empírica (cómo es percibida por el propio sujeto y por los demás) y ‘muerte con dignidad’. Mientras que los dos primeros sentidos darían respuesta a “lo que significa en sí” el tercero tendría que ver con “los valores y pensamientos asociados a esta percepción”.

La idea de muerte con dignidad se desarrollará después de esclarecer los términos de autonomía, control y autodeterminación puesto que no puede comprenderse qué significa esta expresión fuera del marco de la autonomía.

a) Sentido intrínseco

Muchos de los estudios que, desde algún punto de vista, tratan sobre la dignidad hacen referencia a un primer nivel intrínseco (Ashcroft, 2005; Chochinov et al., 2002; Leung, 2007; Pullman, 1996; Sulmasy, 2005). Algunos autores se han referido a éste como *dignidad fundamental* que designaría el valor intrínseco e inalienable que toda persona posee y que no puede variar ni erosionarse en función de las circunstancias (Leung, 2007; Pullman, 2004). Esta idea de dignidad tendría que ver con que “la persona no conoce gradación [...] esta dignidad no puede ser destruida ni aniquilada, es indestructible. [...] no depende de la realización de las capacidades de la persona” (Seifert, 1995, p. 139 citado en Torralba (2005, p. 357)).

Este sentido de dignidad es al que se alude cuando se habla de los derechos humanos: “la libertad, la justicia y la paz en el mundo tienen por base el reconocimiento de la dignidad intrínseca y de los derechos iguales e inalienables de todos los miembros de la familia humana” (Organización de las Naciones Unidas, 1948). Sulmasy (2013) en su interesante análisis lógico-conceptual también recalcó que la dignidad es un valor intrínseco que alguien posee en virtud de su condición humana.

Desde un punto de vista histórico, esta noción intrínseca de dignidad a menudo se ha fundamentado en discursos religiosos. Por ejemplo, suele mencionarse que la dignidad se fundamenta en la idea de que el ser humano ha sido creado a imagen y semejanza de Dios, tal y como se relata en el libro del Génesis (Gen 1: 26-27). Sin embargo, esta concepción de dignidad ha quedado desdibujada y, a menudo, substituida por el concepto más amplio de sacralidad o santidad de vida[22] que también haría referencia a la idea de que la persona es un absoluto y un fin en sí misma (Jacobson, 2009a; Jordan, 2010; Pullman, 1996). La idea de que la vida es una realidad sagrada tiene su origen en el presupuesto de que la vida humana, en sí misma es sagrada y trascendente; y, en consecuencia violarla o destruirla podría entenderse como un sacrilegio injustificable (Kass, 1990). Aunque podría pensarse que la idea de sacralidad tiene que ver con un principio religioso, autores como Bayertz (1996, p. xiii) señalan que no es necesariamente así. Según este autor, la santidad de vida podría definirse cómo “el principio moral absoluto que protege la vida de ser dañada”. En este sentido, tal y como apunta Keenan (1996), el término ‘santidad de vida’ referiría no tanto a un deber hacer –en calidad de esta santidad– sino a lo que no se puede hacer: en este caso, transgredir los límites de la vida. Sea como fuere, la reminiscencia a la herencia judeocristiana en el contexto occidental es clara: mientras que para algunos autores católicos la dignidad seguiría siendo el reflejo dela *imago Dei,* para otros sería expresión de una espiritualidad secularizada, no dependiente de ninguna tradición religiosa.

Por el contrario, la asunción de la sacralidad de la vida ha sido puesta en entredicho por filósofos como Singer (1983; 1988) o Kuhse (1981), quienes

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[22] ‘Santidad de vida’ (*sanctity of life*) es un concepto desarrollado principalmente en el ámbito anglosajón que podría equipararse a la noción de dignidad humana, que tiene su origen en el ámbito europeo. Ambos conceptos tienen en común que se presentan como aquella cualidad a partir del cual la vida humana se concebiría como sagrada e inviolable. La expresión ‘santidad de vida’ empezó a predominar en los debates académicos y civiles de forma paralela al nacimiento de la bioética. Según Bayertz (1996, pp. vii–viii), tres fueron los escenarios en los que se utilizó el término de ‘santidad de vida’ como argumento fundamental para proteger la vida humana: 1) En las Cortes Supremas de Estados Unidos que empezaron a legislar a favor del aborto. 2) En los debates sobre el final de la vida en relación a los tratamientos invasivos (qué momento es el oportuno para terminar con un tratamiento [por ejemplo en las unidades de cuidados intensivos]) y en relación a la legislación y práctica de la eutanasia y del suicidio asistido. 3) En las discusiones relativas a la intervención tecnológica en la reproducción humana y en la inseminación artificial. En estos tres escenarios ‘la santidad de vida’ aspiraría a tener un estatus normativo en las legislaciones de los diferentes países de modo que se protegiera eficazmente a cada individuo desde su concepción hasta su término natural. Sin embargo, el concepto de ‘santidad de vida’ no está exento de polémica y ambigüedad. Por un lado, se cuestiona si hace referencia a la vida humana de forma exclusiva o si por el contrario también incluiría otras formas de vida animal o vegetal. Por otro lado, algunos detractores también cuestionan cuál es el origen y fundamento de esta ‘santidad’ y alegan que no es posible huir de un postulado religioso (Kuhse, 1981; Singer y Kuhse, 1988).

asumiendo la ética utilitarista del ámbito anglosajón, han insistido en que no existe esta supuesta 'santidad' y que su defensa solo es comprensible desde un marco fideísta y no desde la lógica racional. Como se verá en el siguiente punto, en el contexto de la literatura científica al final de vida, la alusión a la dignidad intrínseca es más bien escasa y no suele considerarse en un plano práctico, aplicado en el ámbito de las ciencias de la salud. Como mucho, se habla de dignidad intrínseca para distinguirla de los otros niveles de dignidad, pero no deja de circunscribirse a un mero apunte teórico. Con esto se quiere decir que la mayoría de estudios hablan de la dignidad en función de cómo los pacientes perciben su identidad en relación a las circunstancias y a la enfermedad, y muy pocos hablan de este sentido intrínseco. No obstante, en algunos estudios sí que se refleja cómo algunos pacientes se quejaron al verse tratados como enfermos o pacientes en lugar de personas, y cómo quienes consideraron la dignidad como un valor irrenunciable tuvieron una actitud más positiva frente a la enfermedad (Chochinov, 2007; Enes, 2003).

b) La dignidad como cualidad empírica

En el segundo nivel estaría la dignidad personal (dignidad dinámica o personal) relacionada con la percepción del individuo y los de su alrededor (Chochinov et al., 2002; Jacelon, 2003; Leung, 2007; Street y Kissane, 2001). Tal y como apuntan Street y Kissane (2001) la dignidad es percibida por una persona dentro de un contexto determinado. Y en este sentido, dignidad es un constructo encarnado y dinámico, sensible a la relación con los demás. Tendría que ver con la imagen que construye el sujeto a partir de la vivencia de la enfermedad: lo que define la dignidad sería único para cada paciente (Chochinov, 2004). Es decir que la dignidad se mediría en términos de construcción subjetiva condicionada por factores físicos, psicológicos y sociales.

En este punto, como ya se ha dicho, destaca el modelo empírico de dignidad de Chochinov et al. (2002), quienes exploraron el sentido de dignidad a partir de la experiencia vivida por pacientes en cuidados paliativos a través de los siguientes ámbitos. El primero es el relacionado con la enfermedad en sí: pérdida de funcionalidad psíquica y corporal, control de síntomas, ansiedad ante la muerte e incertidumbre del pronóstico. El segundo es el relacionado con cómo el sujeto gestiona la situación y se percibe a sí mismo: sentido de la continuidad personal, preservación del rol social, espíritu de lucha, autonomía, sentido de la vida, desesperanza y aceptación de la enfermedad, entre otros. Y, el tercero, es el relacionado con los factores sociales: privacidad, soporte social, calidad del cuidado, manejo de los asuntos no resueltos, dependencia de los demás y percibirse como una carga. Aunque otros autores también han desarrollado otros modelos de comprensión de dignidad, podría decirse que aportan poco más al ya planteado por Chochinov y su equipo (2002).

Como consecuencia de la creciente atención por preservar el sentido de dignidad, se han construido y validado algunos instrumentos para evaluar su percepción en pacientes con enfermedad avanzada. En el año 2008 Chochinov et al. (2008) publicaron la primera escala para cuantificar la percepción de dignidad de los pacientes (*Patient Dignity Inventory* [Inventario de dignidad del Paciente]), partiendo de las categorías halladas en su modelo empírico de dignidad (Chochinov et al., 2002). Poco más tarde, Periyakoil et al. (2009; 2010) construyeron dos escalas (*Dignity Card-Sort Tool* y *Preservation of Dignity Card-Sort Tool*) para evaluar los factores que podían influir en la pérdida y salvaguarda de dignidad al final de la vida; y, recientemente Vlug et al. (2011) otra escala para analizar la auto-percepción de dignidad. En la actualidad, el *Patient Dignity Inventory* es el que ha tenido mayor acogida en el ámbito clínico y ha sido traducido, validado y utilizado en países como Alemania, Italia y España (Albers et al., 2011; Guo y Jacelon, 2014; Hall et al., 2009; Rullán et al., 2015; Vehling y Mehnert, 2014).

Por último, otro uso común de dignidad tiene que ver con nociones como respeto, mérito, estima, juicio o valoración (dignidad interpersonal) De hecho, esta acepción es la más fiel a la antigua voz romana de *dignitas* y se corresponde con las distintas definiciones de dignidad tal y como aparecen en algunos diccionarios (Merriam Webster, 2017; Real Academia Española, 2014a). En este sentido, se concebiría la dignidad como el atributo, mérito o estima que la persona acumula durante su vida (Sulmasy, 2013). Está muy relacionada con cómo la persona es reconocida por los demás y con la dignidad en sentido moral. Es decir, con el hábito de actuar de forma coherente con los principios, virtudes y valores (Nordenfelt, 2004).

Como se ha señalado, el término dignidad a menudo se fundamenta partiendo de la noción de autonomía. Asimismo, es común la alusión a la pérdida de autonomía como motivo por el cual desear adelantar la muerte y como derecho (el de autonomía) a través del cual defender la muerte voluntaria[23]. De esta forma, en el siguiente capítulo se tratará de abordar el concepto de autonomía en el contexto de final de vida.

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[23] Baste considerar que en algunos países, como por ejemplo en Estados Unidos, al movimiento de "Derecho a morir dignamente" se le llama o se le ha llamado *Self-determination Act*.

Capítulo 4. La autonomía y control en la literatura biomédica en el contexto de final de vida

En el ámbito biomédico, la autonomía actualmente se concibe como un modelo y un valor irrenunciable. En 1978 con el informe Belmont (National Institutes of Health, 1979) y poco después con los *Principles of Biomedical Ethics* de Beauchamp y Childress (1979) se formalizaron las tesis del extendido modelo principialista de bioética donde precisamente la autonomía se erige como pilar fundamental (Callahan, 2002; Nordgren y Fridlund, 2001).

Con frecuencia, se define autonomía como "la capacidad humana de autodeterminación e independencia" relacionada con la elección racional libre (Mesler y Miller, 2000). Aquí puede observarse que, a pesar de que en la práctica clínica autonomía podría entenderse, por ejemplo, como pérdida de funcionalidad física o de control sobre las actividades de la vida diaria, en algunos discursos se relaciona con la identidad personal y con el sistema de valores y creencias del paciente. En este sentido encuadra perfectamente la descripción que Feyto (2011) propone sobre el tema en un editorial sobre *Los fundamentos de Bioética* de Diego Gracia:

> "La beneficencia y la autonomía son principios que se explican desde la referencia a un sujeto, portador de un sistema de creencias, desde el cual define su proyecto vital y, conforme al cual determina los bienes que le permiten llevarlo a cabo. Este es un ámbito privado, en el que nadie puede ni debe interferir. Se refiere a los máximos a los que una persona aspira, los que dotan de sentido su actuación moral, la guía de sus comportamientos y convicciones" (p. 10).

Como ya se ha mencionado, autonomía a menudo también se entiende como control y como autodeterminación. Como control referiría a los ámbitos sobre los que los pacientes tienen cierto sentido de dominio y a su influencia sobre cómo se perciben (Chochinov, 2004, 2007). Es decir, tendría que ver con la funcionalidad física (Chochinov et al., 2002), con la capacidad de mantener las actividades de la vida diaria (Chochinov et al., 2002; Schroepfer et al., 2009; Volker et al., 2004b), con mantener la independencia respecto a los demás (Chochinov et al., 2007; Östlund et al., 2012), con el recibir información adecuada y decidir en coherencia con los propios valores y posibilidades

(Lavoie et al., 2011), así como con la forma en que el paciente –y su entorno– se percibe a causa de esta pérdida de control. En cambio, autonomía como autodeterminación, estaría ligada fundamentalmente al derecho a elegir y controlar el proceso de final de vida (Chapple y Ziebland, 2006; Lee et al., 1996).

Parte de la complejidad en definir lo que se entiende por autonomía es que aparece en múltiples contextos bajo aspectos distintos. En la literatura científica sobre el final de la vida, autores como Volker et al. (2004b) o Schroepfer et al. (2009) han señalado la importancia del control en pacientes con enfermedades avanzadas. Los primeros han descrito con precisión las áreas sobre las que pacientes desean tener cierto tipo de dominio (Volker et al., 2004b), así como las estrategias que pueden utilizar los profesionales de salud para favorecer este control (Volker et al., 2004a); y Schroepfer et al. (2009) han detallado qué rol juega el sentido de control en pacientes en estados terminales de su enfermedad.

En la meta-etnografía publicada sobre pacientes con DAM se describió la autonomía o control bajo tres aspectos (Monforte-Royo et al., 2012). Por un lado, el déficit o la disminución del control se presentaron en conexión con la percepción de pérdida de la propia identidad ligados al deterioro físico resultado de la enfermedad (pérdida de la funcionalidad física, incontinencia, etc.). Esta pérdida de control se asoció a síntomas de distrés emocional: sentimientos de inutilidad, desesperanza, ansiedad o depresión; así como con la pérdida o transformación del rol social. El segundo aspecto, hizo referencia a la falta de dominio sobre la propia vida y sobre el futuro como consecuencias de esta pérdida de control sobre uno mismo. Y el tercero, hizo alusión a cómo la posibilidad de control sobre las circunstancias del proceso final de la enfermedad, al menos sentir que se sigue teniendo cierto dominio sobre algún aspecto de la vida, alivia el sufrimiento y ansiedad en estos pacientes.

Otros autores como Ganzini et al. (2006) o Emanuel et al. (2000) han presentado el final de vida de pacientes con enfermedad terminal, como un progresivo deterioro de su autonomía y han encontrado en el suicidio asistido o eutanasia una forma de superar esta limitación. Es decir, el decidir sobre las circunstancias de la muerte supondría, para estos pacientes, estar por encima de la pérdida de control que supone una enfermedad mortal.

A pesar de la alta aceptación del suicidio asistido y eutanasia en los lugares donde están despenalizadas –recogida a través de encuestas sobre la actitud u opinión pública de la sociedad general en torno a este tema–, un dato interesante es que muy pocas personas lo acaban solicitando realmente (Onwuteaka-Philipsen et al., 2003). Este hecho, en parte, puede justificarse porque el tener cierto control sobre las circunstancias que se ha mencionado más arriba, puede ser vivido como una forma de libertad, autodeterminación y alivio para los pacientes (Coyle y Sculco, 2004; Monforte-Royo et al., 2012). En otras palabras podría decirse que, en la medida en que los pacientes pueden mantener cierto grado de control, el recurrir a la muerte no se vería como algo necesario.

Volviendo al primer punto, el último campo desde el que se habla de autonomía es en relación con la dignidad percibida en personas al final de la vida. Algunos autores han descrito la relación que, en efecto, hay entre ambos conceptos (Ho et al., 2013; Pullman, 2004; Street y Kissane, 2001; Van Brussel, 2014), sin embargo, tras revisar la literatura, se hacen evidentes los múltiples sentidos que se le da a este binomio, las distintas conclusiones que se derivan de los estudios y la presencia no explícita de presupuestos sobre quién es la persona y sobre el valor de la vida.

En síntesis se podría decir que autonomía, en un sentido amplio, aparece como factor crucial en pacientes en fases avanzadas de la enfermedad, vinculada a la propia identidad (dignidad), y al deseo de control sobre las circunstancias y el proceso de final de vida.

Capítulo 5. Dignidad y autonomía en la literatura biomédica en el contexto de final de vida

Como se ha dicho, a pesar de que se ha hablado de dignidad-autonomía como lugar común (Walsh y Kowanko, 2002) no es claro en qué medida estos conceptos se relacionan entre sí. En este punto se tratará de describir, en primer lugar, qué se entiende por ‘muerte con dignidad’ como expresión inseparable tanto de autonomía como de dignidad y, en segundo lugar, qué vínculo se ha encontrado en estudios científicos sobre este binomio.

5.1 ‘Muerte con dignidad’

El concepto de muerte con dignidad, como se ha dicho más arriba, alude al derecho a elegir una muerte voluntaria en pacientes con un sufrimiento extremo y sin expectativas de curación (Sampaio, 1992). En la actualidad, los países o regiones que han legalizado prácticas de ‘muerte digna’ son en el continente americano: Oregón (1994), Washington (2008), Montana (2008), Vermont (2013) y California (2015) en Estados Unidos; Canadá muy recientemente, desde julio de 2016; y en Europa en Suiza (1942)[24], Holanda (2001), Bélgica (2002) y Luxemburgo (2008) (“History of death with dignity,” s.f). Y en otros muchos países existen movimientos semejantes que promueven la despenalización del suicidio asistido y de la eutanasia. También existen casos en los que por un tiempo alguna de estas prácticas se ha legalizado y al cabo de un tiempo se ha vuelto a penalizar como es el caso del Territorio del Norte en Australia, Colombia y Nuevo México[25].

Aunque algunos de estos movimientos empezaron haciendo hincapié sobre el ‘derecho a morir’, finalmente el lema ‘muerte con dignidad’ se ha impuesto como eslogan que engloba las posiciones a favor de la muerte voluntaria (Street y Kissane, 2001)[26]. Autores como Pannuti y Tanneberger

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[24] Suiza ofrece un ejemplo singular puesto que es el único país donde está despenalizado el suicidio asistido sin la participación de un médico. La ayuda en le morir está permitido bajo condiciones estrictas y siempre bajo el supuesto de que se ayuda a morir por razones altruistas. Ver por ejemplo Hurst y Mauron (2003).

[25] La eutanasia o suicidio asistido en estos países estuvo despenalizada entre los años 1995 a 1997, 1998 a 2000, y 2014 respectivamente.

[26] Algunos de los nombres que se han utilizado hasta el momento son: Derecho a Morir (con Dignidad), Dignidad, Morir con Dignidad, Derecho a la Autodeterminación (o a Elegir), etc.

(1993), Coope (1997) o Johnson (1998) han visto las limitaciones y ambigüedades de este término y se han cuestionado si es verdaderamente ‘digna’ la muerte que plantean estos movimientos autodeterministas. No obstante, es recurrente encontrar en los medios de comunicación noticias que hagan referencia unívocamente a la ‘muerte con dignidad’ aludiendo al deseo de morir de pacientes en situaciones extremas o a la eutanasia y suicidio asistido[27].

De una forma clara, Street y Kissane (2001) en el estudio ya citado enfatizaron la sutil manipulación del lenguaje que puede llevarse a cabo:

> “Imágenes emotivas de indignidad son frecuentemente utilizadas para definer dignidad por asociación. Por ejemplo, en la siguiente transcripción de un caso llevado a las cortes sobre el grupo de eutanasia voluntaria *Compassion in Dying* versus el estado de Washington, la dignidad es asociada con ser adulto y separado de la dependencia infantil.
>
> Un adulto terminal, competente y enfermo… Tiene un fuerte y libre interés en elegir una muerte digna y humana antes que ser reducido a un estado infantil de inutilidad, sedación e incontinencia.
>
> Esta asociación inmediatamente engendra una respuesta emcocional de acuerdo y disgusto en muchas personas. El uso de palabras como inutilidad, sedación e incontinencia se ajusta a los miedos de muchos, ya que la declaración de la Corte no especifica en qué consiste una muerte digna y humana” (p. 95).

En otras publicaciones también se encuentran afirmaciones semejantes. Por un lado, usando un lenguaje metafórico y emotivo que propicia esta respuesta sensible (Kade, 2000; Quill, 1991). Y por otro, reafirmando cuestiones como la importancia de ser autónomo o independiente como valores absolutos, sin tener en cuenta otros criterios de valoración. Por ejemplo, el primer caso publicado sobre una paciente que murió por suicidio asistido refleja

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[27] Un caso emotivo sería por ejemplo el de los gemelos Marc y Eddy Verbessem de Bélgica. Eran sordos de nacimiento (1968) y con el tiempo fueron diagnosticados de una enfermedad ocular degenerativa por la que se iban a quedar ciegos. Ante tal pronóstico solicitaron morir bajo la eutanasia, práctica a la que tuvieron acceso en el 2014. Lo destacable de este caso es que cuando murieron todavía no se habían quedado ciegos –ni padecían síntomas relacionados con la ceguera– pero alegaron padecer un sufrimiento psicológico insoportable debido a la anticipación de su pronóstico (Gordts, 2013).

perfectamente los puntos que se han señalado (Quill, 1991). El médico que trató a Diane, una mujer diagnosticada con una leucemia terminal, insiste en que era una persona extraordinaria, independiente, que deseaba morir y, sobre todo, controlar las circunstancias de su final de vida. El artículo cierra con dos emotivas despedidas: la del médico con su paciente y la de la paciente con su familia:

> “cuando mos conocimos, estaba claro que ella sabía lo que hacía, que ella estaría más horrorizada de quedarse y sufrir. En nuestra triste [*tearful*] despedida, ella me prometió una reunión en el futuro en su lugar preferido al borde del Lake Geneva, con dragones nadando al atardecer […] Dos días más tarde, su marido me llamó diciendo que Diane había fallecido […] La encontraron en su cama, cubierta con su fulard preferido. No había signos de lucha. Parecía estar en paz […] Su marido y su hijo quedaron muy tranquilos. Hablamos de la persona remarcable que Diane había sido…” (Quill, 1991, p. 693-694).

A grandes rasgos, podrían señalarse algunas coordenadas para comprender a qué se denomina ‘morir con dignidad’. El presupuesto de partida, tiene que ver con el llamado ‘argumento de la autonomía’, esto es la consideración de que la autonomía y la autodeterminación son los valores que fundamentan el sentido de dignidad de una persona y que hay que respetar como ‘sentimiento privado’ (Batavia, 2000; Crigger et al., 1990; Sampaio, 1992). Autonomía como fundamento de la dignidad se entiende en dos sentidos. Por un lado, refiere al derecho de cada paciente a ser respetado en sus valores y decisiones y en consecuencia pueda actuar conforme a ellos; y por otro, a la posibilidad de mantener las capacidades físicas y cognitivas sin las cuales no podría ser independiente. Bajo este prisma, cualquier persona tendría derecho a poner fin a su vida en el momento en que no hubiera esperanza de curación y se perdiera la calidad de vida. Con frecuencia, subsistir dependiendo de respiradores y sondas de alimentación, es visto como una forma ‘indigna’ e inhumana de vivir, como un hecho artificial que liga la vida de una persona a una máquina alargando su existencia de manera innecesaria (Sampaio, 1992). De nuevo, la alusión a que la persona tiene el derecho de vivir como quiera sus últimos instantes así como de ponerle término también es constante; incluso es visto como una forma de compasión y solidaridad para con la familia y el enfermo (Compassion & Choices, 2008).

En esta línea, Chin et al. (1999) y Ganzini et al. (2003; 2009; 2002) entre otros, han profundizado en algunas de las características de los pacientes que han solicitado suicidio asistido y que da luz sobre la relevancia del argumento de la autonomía. Por ejemplo, a un mayor nivel educativo, económico y a una menor adhesión o pertenencia a tradiciones religiosas/espirituales es más frecuente que se dé un mayor deseo de autonomía y un mayor deseo de morir. Otros investigadores también han señalado cuáles son las causas y factores relacionados que conducen a los pacientes a solicitar estas prácticas (Ganzini et al., 2003; Lee et al., 1996; Schroepfer, 2008; Sullivan, Hedberg y Fleming, 2000; Sullivan et al., 2001; Tolle et al., 2004; Wilson et al., 2007). A pesar de que a menudo se señalan como causa de la muerte voluntaria cuestiones económicas, el miedo a ser una carga para los demás o la falta de control sobre el dolor (Lee et al., 1996); estos autores subrayan cómo el denominador común de los pacientes es la importancia que atribuyen a la pérdida de autonomía y control sobre el momento de morir. Chin et al. (1999) en el estudio de casos-controles que llevaron a cabo, confeccionaron dos grupos distinguiendo entre los pacientes con enfermedad terminal que solicitaban el suicidio asistido y los que no. Destacó que el grupo compuesto por pacientes que deseaban morir tenía más control sobre sus funciones físicas y actividades que el otro grupo. Sin embargo, destacaba en ellos el miedo a una pérdida de control futuro, es decir, "fueron sus valores personales los que les llevaron a tomar una dirección u otra, no la intensidad objetiva de sus incapacidades" (White y Callahan, 2000, p. 334).

5.2 La relación entre autonomía y dignidad en la literatura biomédica

Como ya se ha dicho, tanto desde un punto de vista teórico como empírico se ha reflejado el vínculo existente entre dignidad y autonomía en pacientes al final de la vida. En los apartados anteriores se ha tratado de definir cómo se entiende cada uno de ellos por separado y, simplificando, podría subrayarse que dignidad en tanto cualidad empírica, puede asociarse a la funcionalidad como pérdida de autonomía y de control e influir en la forma en que la persona se percibe a sí misma (identidad). Autonomía, en tanto que valor asociado a la identidad personal puede asociarse con dignidad. Es decir, algunas personas entienden que la vida pierde su valor –concebido como dignidad– en la medida en que pierden el control sobre su vida y circunstancias y ya no pueden disfrutar de las actividades cotidianas.

Street y Kissane (2001) han encuadrado la dignidad como autonomía y autodeterminación en el contexto del discurso a favor de la muerte con dignidad. Y han señalado el reduccionismo que entraña concebir dignidad como calidad de vida y la importancia de un cuidado adecuado por parte de los profesionales de salud. Asimismo, en palabras de una de sus pacientes, han definido estos conceptos a la luz de ser capaz de definir los propios límites y valores, en lugar de que sean los demás quienes lo hagan.

Nordenfelt (2004) habló de este binomio vinculándolo a conceptos como identidad, integridad, imagen personal, respeto y confianza. A causa de la enfermedad es frecuente que los pacientes asocien la transformación de su imagen física a la fragmentación de su identidad. El resultado es la aparición de una pérdida de autoestima y confianza, así como la ruptura con un entorno que ya no les ve igual (Jacelon, 2003; Street y Kissane, 2001).

Chochinov et al. (2002) también encontraron en su estudio cualitativo sobre la dignidad, categorías asociadas a autonomía, control o independencia. En este sentido es interesante distinguir entre los distintos niveles desde los que entienden dignidad. El primero, referiría al ámbito de la funcionalidad: cómo se ve afectada la autonomía o independencia como consecuencia de la enfermedad; y el segundo, a un ámbito más interior: capacidad de seguir manejando la vida y elegir según los valores personales.

Enes (2003) en un estudio fenomenológico observó que tanto pacientes como profesionales sanitarios relacionaron la noción de dignidad con tener control sobre las decisiones, sobre el cuerpo, sobre la conducta y sobre lo que sucede. Esta forma de control también fue relacionada con preservar la identidad. Y en otro estudio desde el punto de vista de los profesionales de salud (Walsh y Kowanko, 2002) se hallaron resultados similares al identificar dignidad con control sobre las circunstancias y acceso a la información para poder salvaguardar la autonomía.

Por último, como ya se ha dicho, un ámbito desde el que se suele hablar de dignidad y autonomía es en las investigaciones sobre el deseo de adelantar la muerte.

En consecuencia a lo planteado en los capítulos anteriores, ahondar sobre cómo se entienden dignidad y autonomía y qué relación existe entre ambas en la experiencia de los pacientes al final de vida resulta crucial para superar los interrogantes que surgen ante la presentada falta de claridad conceptual en la literatura científica.

Dando un paso más, tal y como afirma Ohnsorge (2015), el debate sobre algunas cuestiones bioéticas con frecuencia se ha dado contraponiendo principios fundamentales. Por ejemplo, tal y como se ha dicho, en el discurso sobre la eutanasia es común la alusión a la defensa de la autonomía, autodeterminación y dignidad; y, paradójicamente es frecuente que se utilicen estos principios para defender posiciones contrarias. Por eso, profundizar sobre cómo perciben su dignidad y autonomía los pacientes al final de la vida, cómo expresan tales percepciones, y cómo son entendidas por sus interlocutores (familiares, profesionales) es uno de los objetivos de esta tesis y el primero de los artículos presentados.

Capítulo 6. La experiencia de la dignidad y de la autonomía en pacientes al final de la vida. Una mirada fenomenológica

Tal y como han afirmado tanto filósofos como profesionales de la salud, ciertamente, la filosofía puede ayudar a profundizar sobre quién es la persona, cuáles son sus dimensiones o qué significa estar sano o enfermo. De forma particular, la fenomenología puede ser un método adecuado para "describir y ordenar la experiencia" así como para conocer y comprender de forma sistemática las percepciones y vivencias en primera persona del sujeto de esa experiencia (Carel, 2011, p. 1). De esta forma, en este capítulo se presentarán algunas nociones de la fenomenología de la corporalidad y de la enfermedad, partiendo especialmente de la filosofía desarrollada por Toombs[28], que tratarán de enmarcar el segundo artículo de esta tesis. El objetivo del segundo artículo es establecer un diálogo entre los datos de los estudios cualitativos (las expresiones verbales obtenidas de los estudios sobre dignidad percibida y autonomía −primer artículo (Rodríguez-Prat et al., 2016)− y los conceptos trabajados desde la fenomenología de la corporalidad desde el análisis toombsiano.

La fenomenología de la corporalidad inspirada y desarrollada por, entre otros, Husserl, Merleau-Ponty y Sartre –los grandes representantes de la filosofía fenomenológica– ha sido aplicada de manera retrospectiva por algunos autores a temas y problemas frecuentes en los campos de la salud y de la práctica clínica. La mirada fenomenológica puede aportar una perspectiva interesante, precisamente porque hace posible una reflexión a partir de la experiencia del paciente, y en este caso de forma particular, teniendo en cuenta vivencias muy concretas relacionadas con la dignidad, control o autonomía a partir de la experiencia del propio cuerpo. Entre estos autores, cabe destacar a Richard Zaner, S. K. Toombs, Drew Leder, Fredrik Svenaeus o

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[28] Toombs, que fue diagnosticada de esclerosis múltiple en 1973, es una autora interesante en el ámbito de la fenomenología de la enfermedad y de la corporalidad, puesto que sus trabajos parten de su formación y su experiencia como paciente de esclerosis múltiple. Actualmente es reconocida como una de las máximas voces en las áreas de fenomenología de la corporalidad en este contexto de enfermedades crónicas. Por la riqueza filosófica y experiencial de su discurso fenomenológico del estar enfermo parece interesante establecer una comparación entre algunos conceptos desarrollados por la autora y los temas que emergieron en los estudios cualitativos sobre dignidad y autonomía.

Havi Carel [29], por ejemplo, que tienen la común preocupación de la deshumanización de la medicina, entendida como la comprensión del cuerpo o enfermedad exclusivamente a través de parámetros mecánicos, naturalísticos o biológicos.

En oposición a la concepción cartesiana del cuerpo como máquina –que puede encontrarse en el núcleo del paradigma moderno biomédico–, la perspectiva fenomenológica tiene como objetivo reevaluar la experiencia de la enfermedad vivida en primera persona. Por ejemplo, a través de la experiencia el cuerpo es percibido como vulnerable, susceptible al dolor, limitado, falible, etc.

El punto de partida de este enfoque es la distinción entre el cuerpo objetivo de la ciencia y el cuerpo vivido de la experiencia. Es importante establecer la diferencia entre estas dos perspectivas. En primer lugar, el cuerpo objetivo es definido como una realidad material, con propiedades físicas (forma, color, textura) similar a otros objetos. Este cuerpo objetivo puede ser estudiado y analizado desde fuera, en tercera persona, bajo la perspetiva del conocimiento neutral de la ciencia natural como en el caso, por ejemplo, de la anatomía, fisiología o neurología. En segundo lugar, el cuerpo vivo y vivido refiere al cuerpo a través de la experiencia subjetiva, como el centro de orientación a partir del cual las dimensiones espaciales del mundo son organizadas, como la capacidad de movimiento, acción y relación con otros seres, como un órgano de sentidos (capaz de sincronizar cualidades sensoriales) y como campo de localización de las sensaciones (Husserl, 1997, pp. 143–161). Mientras que el cuerpo objetivo ocupa una posición en el espacio, junto a otros objetos, en una dimensión espacial geométricamente determinable, el cuerpo vivido inhabita en el espacio y mantiene una relación simbiótica con él.

Gracias a este nuevo paradigma del cuerpo vivido, en contraste con el paradigma del cuerpo objetivo, es posible dar voz a la experiencia de los

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[29] Ver por ejemplo: Zaner (1971), Toombs (1988, 1992, 2001, 2004), Leder (1990). Por el mismo motivo que Toombs, el tabajo de Havi Carel (2007, 2011; 2013) merece especial atención. La perspectiva de Carel en torno a la fenomenología de la enfermedad se basa en su propia experiencia como paciente de una enfermedad respiratoria (*lymphangioleiomyomatosis*).

pacientes y rehumanizar ciertos aspectos de la práctica clínica. De esta forma, serviría de contrapeso a la excesiva objetivación o naturalización del proceso de enfermedad en la que a menudo se ha caído.

Algunas características del cuerpo vivido según Toombs serían:

1) "El cuerpo vivido no es un objeto similar a otro objeto físico o animado. Sino el medio a través del cual aprehendo el mundo e interactúo con él" (Toombs, 2001, p. 5). Mi organismo encarnado es siempre vivido, experimentado dentro de un entorno.

2) La relación con el cuerpo vivido es existencial, más que objetual u orgánica. Como dice Sartre, es por eso que yo no puedo entender mi cuerpo como un "organismo biológico" o una suma de órganos (cfr Toombs, 2001, p. 52).

3) Hay una identificación esencial con mi cuerpo por la que no percibo ninguna separación entre mi cuerpo y el yo (*self*) por la que puedo expresar "yo soy mi cuerpo" antes que "yo poseo un cuerpo".

4) El cuerpo vivido implica:

- En términos heideggerianos *estar-en-el-mundo*. Esto es que el cuerpo vivido se encuentra temporal y espacialmente situado. Es el centro de las coordenadas de 'mi mundo' por lo que no puedo separarme del aquí y del ahora ni tomar distancia respecto a mi cuerpo.

- Poseer una corporalidad intencional que revela una relación dinámica entre el cuerpo y el mundo por la que se hacen posible los proyectos existenciales que expresan la propia personalidad (Toombs, 2001, p. 6).

- Generar significados como consecuencia de la interacción cuerpo-mundo. El cuerpo vivido percibe el mundo y a través de su vivencia lo integra de una forma unitaria y le da un nuevo significado. En este proceso el sujeto encarnado refleja la propia identidad a través del propio lenguaje corporal (manera de andar, manera de moverse, etc.), proyecta un significado a la vez que se identifica y es reconocido (cfr Toombs, 2001, p. 7).

5) La experiencia del propio cuerpo es limitada. No puedo aprehender todos los aspectos de mi cuerpo de una forma total o directa. El cuerpo es en parte, extraño para mí mismo en cuanto que en él se dan "eventos, procesos y estructuras sobre las cuales no tengo control y sobre las cuales no puedo tener una consciencia o un conocimiento total" (Toombs, 2001, p. 7). Esta experiencia de "extrañeza" del cuerpo vivido es aprehendido, en cierto sentido, como un "otro" (*other than me*) y es especialmente recurrente en la enfermedad. Concretamente la autora utiliza la metáfora de la enfermedad como una presencia escondida que necesariamente está fuera del control del sujeto.

Partiendo de las características del cuerpo vivido según Toombs resulta posible encontrar este esquema en las vivencias de pacientes que se encuentran al final de sus vidas. En primer lugar, podría decirse que existe un cuatrinomio inseparable yo-cuerpo-mundo-otros. El cuerpo dañado por la enfermedad[30] "no solo ha interrumpido nuestra sensación normal de salud. Ha abierto una enorme falla o fisura en nuestro mundo" (Morris, 1991, p. 35). La enfermedad marca los límites del contexto existencial en el que vive el sujeto desde que recibe su diagnóstico (ámbito del conocimiento) hasta que percibe los primeros síntomas de la enfermedad (ámbito del padecer) sin poder distanciarse de sí mismo. El impacto de la enfermedad sobre el cuerpo suele generar un cambio en la identidad personal:

> "Todo el que ha soportado un período de dolor intenso probablemente se ha hecho, en silencio o abiertamente, las siguientes preguntas, incesantes: ¿Por qué yo? ¿Por qué me sucede esto? ¿Por qué no termina? De súbito, carecemos del conocimiento que necesitamos. La combinación de duda y temor puede disparar una avalancha de preguntas relacionadas. ¿Cómo me voy a ganar la vida si no puedo ir al trabajo? […] ¿Estoy condenado a pasar el resto de la vida con dolores? Estar con dolor a menudo es estar en crisis. Es un estado en que experimentamos más que incomodidad física. El dolor no solo ha interrumpido nuestra sensación normal de salud" (Morris, 1991, p. 35).

El cambio de imagen física, la pérdida de los roles sociales y profesionales, la incapacidad de acometer acciones habituales antes de

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[30] En la cita original el sujeto es dolor y no enfermedad.

contraer la enfermedad son indisociables del cuestionamiento sobre la propia identidad: ¿quién soy, qué me queda cuando lo voy perdiendo todo, cuando ya no me reconozco?

La enfermedad replantea mi situación espacio-temporal de ser-en-el-mundo de modo que la pérdida de la vida silenciosa de los órganos” que es la salud (Le Breton, 1999) se torna ruido en la conciencia a través de todos los movimientos automáticos y ‘silenciosos’ que en la enfermedad no pueden darse por supuesto: respirar, comer, ir al baño, bañarse, desplazarse, coger determinados objetos, etc. En la enfermedad, la persona que ha contraído alguna discapacidad es especialmente sensible a la relación inseparable cuerpo-mundo. De esta forma, la capacidad de expresión de la propia identidad también se ve condicionada ante el futuro incierto, el límite de las posibilidades y la pérdida de actividades que la persona percibía que la definían. En un nivel más funcional también se puede perder esta capacidad de expresión: la manera de moverse, de hablar, de relacionarse con el entorno puede verse truncada a través del cuerpo enfermo que a la vez afecta a cómo soy visto y reconocido por los demás. Por último, la enfermedad hace evidente los límites del cuerpo humano. El sujeto no tiene un control absoluto sobre su cuerpo, del mismo modo que no lo tiene sobre “la vida de sus órganos”. En este punto puede generarse la paradoja de que se dé cierta extrañeza del cuerpo: que el sujeto no se reconozca en su cuerpo o que vea la enfermedad como una intromisión ajena a él mismo que consume su vida.

En los verbatims[31] de los participantes de los estudios cualitativos sobre el DAM, esta idea puede observarse a través de lo que podríamos llamar ‘identidad dividida’, es decir, bajo la visión dualista de que existen dos ‘yo’: el ‘yo’ que uno era antes de contraer la enfermedad y el ‘yo’ que se da durante la enfermedad. Algunos de los pacientes se refirieron a sí mismos en términos de ’yo auténtico‘ y de ’yo enfermo‘. El yo auténtico fue descrito como el auténtico yo (digno), que desea vivir y define verdaderamente quién es la persona y

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[31] El término *verbatim* hace referencia al uso exacto de una cita o sentencia. En metodología cualitativa los verbatims refieren a las citas (en inglés también *quotations)* extraídas de entrevistas o discursos transcritos, narrativas escritas o de estudios originales obtenidas de estudios primarios.

cómo quiere ser recordada. En cambio, el yo enfermo fue visto como inauténtico, inútil, sin ganas de seguir viviendo debido a la pérdida de calidad de vida. Tal y como se observa en los estudios cualitativos, la vivencia de la enfermedad, la percepción de la propia identidad y dignidad, el impacto de las relaciones sociales sobre uno mismo, etc. son realidades dinámicas, fluctuantes e incluso ambivalentes. Retomando la idea que encabezaba este capítulo, en efecto, la fenomenología puede aportar algunas coordenadas interesantes para comprender la experiencia de los pacientes teniendo en cuenta que su objeto es ese mundo oscilante de la enfermedad que se presenta a la conciencia. La huella de la enfermedad en tanto que tiene una impronta biográfica, puesto que afecta a toda la persona, no puede ser explorada desde ámbitos aislados como lo sería atender solo a la dimensión física u orgánica de la enfermedad, sino desde una perspectiva más amplia que atienda también a los aspectos vivenciales y existenciales de la persona. De esta forma, en el segundo artículo de esta tesis ‘A philosophical view on the experiences of dignity and autonomy through the phenomenology of illness’ (Rodríguez-Prat y Escribano, 2017), parafraseando a Havi Carel (2011), se presenta la fenomenología no como un sistema cerrado sino como una práctica capaz de ahondar y sistematizar la experiencia humana. En este segundo artículo, se quiso partir de los temas que emergieron en el primer artículo precisamente para conectar la realidad clínica en la que se encuentran tantos pacientes, con la construcción teórica planteada principalmente por Toombs. De nuevo se quiere insistir en la idea que ha fundamentado esta tesis: profundizar en los mismos conceptos desde miradas distintas pero sobre todo complementarias.

Capítulo 7. La muerte humana: entre lo biológico y lo biográfico

En este capítulo, se pretende enmarcar el fenómeno del deseo de adelantar la muerte teniendo en cuenta algunos conceptos desarrollados desde la filosofía y antropología sobre la muerte y el morir.

La aproximación al fenómeno de la muerte es compleja. Desde un punto de vista físico nos encontramos con cierta indeterminación (¿cuál es el momento *exacto* en el que se *produce* la muerte?). Desde una perspectiva antropológica vemos cómo ahí donde hay constancia de la existencia de *homo sapiens* hay evidencia de que la muerte ha sido objeto de reflexión y de representación[32]. Y desde un punto de vista filosófico podemos observar cómo no hay sistema que no haya abordado el tema de la muerte.

Aceptando la limitación que supone pretender enmarcar un fenómeno concreto como lo es el deseo de adelantar la muerte a partir de unos apuntes breves sobre el óbito humano, se tratará de iniciar la reflexión sobre qué es la muerte, qué experiencia se puede tener de ella y qué elementos del DAM, expresado por pacientes con enfermedades avanzadas, pueden identificarse como una manifestación propia de la cultura de la muerte en el marco de la sociedad occidental.

7.1 Marco preliminar

La muerte es una realidad común a todos los seres vivos que tiene que ver con el término de la vida, con el fin de las operaciones de un organismo y con la corrupción de su naturaleza (*physis*). Esta idea de la muerte que podría definirse como física pondría de manifiesto que el morir iguala a todos los seres vivos y hace inevitable el proceso de descomposición y destrucción inscrito en la naturaleza. Sin embargo, la muerte humana plantea algunos interrogantes que trascienden la dimensión física. Desde un punto de vista clínico determinar el momento de la muerte de alguien, como se verá más adelante, no responde a una cuestión fija, calculable o fácilmente objetivable. Tras la muerte de alguien es posible que algunas de sus funciones sigan en activo. Asimismo,

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[32] Ver por ejemplo Edgar Morin (1994), Hans Jonas (1992).

desde un punto de vista clínico, el establecimiento del momento en que se produce la muerte parece que ha obedecido más a una labor de consenso que al hallazgo del 'instante' real (Arregui, 1994; Schumacher, 2011; Youngner, Arnold y Schapiro, 1999).

Desde un punto de vista fenomenológico, entendido desde la presencia de la muerte en la conciencia humana y su significación sobre la vida, se constata que la muerte en la persona no puede ser solo una cuestión o un acontecimiento biológico (*physis*) que se da al término de la vida sino que es una certeza biográfica que acompaña al ser humano el transcurso de su existencia. La forma de vivir el tiempo en el ser humano permite anticipar la muerte y vivir con la conciencia de la propia mortalidad: el presente es incomprensible fuera de su proyección en el futuro. En este sentido, la anticipación de la muerte podría presentarse como la reflexión más radical ya que determina la vida humana. También podría decirse que la experiencia de la muerte es inseparable de la mediación racional porque, en tanto que el ser humano es consciente de su finitud, puede establecer unas metas organizadas en torno a un fin o a un proyecto vital, que le den un sentido (Arregui, 1994; Thielicke, 1984). Asimismo, la muerte, a pesar de ser una realidad que acompaña la vida humana, no aparece como una realidad translúcida. Es por esto que la falta de inteligibilidad absoluta de la muerte −no hay una experiencia en primera persona sobre la muerte ni sobre lo que ocurre en el más allá, no siempre es clara la causa del *exitus*, etc.− marca una brecha insalvable respecto a la muerte biológica. La muerte, entonces, se presenta como el enigma fundamental de la vida convirtiendo al hombre en un interrogante para sí mismo.

La anticipación de la muerte en la conciencia humana genera una respuesta afectiva y emocional (*pathos*) que a su vez puede redundar en el plano del comportamiento individual y social (*ethos)*[33]. La muerte como *pathos* puede ser temida, sufrida e incluso deseada de forma anticipada. En las concepciones modernas de la muerte y del dolor, la tecnificación de la medicina ha supuesto un cambio en la forma de sentir y vivir la muerte y la enfermedad

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[33] La impronta pática de la anticipación de la muerte podría vivirse en forma de miedo, angustia, ansiedad, desmoralización, desesperanza, anedonia, etc.

(Ariès, 1984, 2005; Illich, 1976; Le Breton, 1999; Thielicke, 1984). El avance desigual de la técnica y de la respuesta ética en torno a éstas ha generado la coexistencia de actitudes paradójicas y contrapuestas en las sociedades occidentales. Por un lado, se habla de la muerte como un tabú, como algo incluso "obsceno" (Gorer, 1955); y, por otro, hay una cierta idealización tanática bajo la forma por ejemplo, de la muerte como opción voluntaria. Trasladando la afirmación de Morris (1991) sobre el dolor, a la muerte, podría decirse que "la humanidad –en todas las culturas y en todos los tiempos– ha comprendido [la muerte], de modo persistente, como un suceso que exige interpretación […] y que obliga a dotarle de sentido" (p. 19)[34].

Tal y como se ha presentado hasta ahora, la significación de la muerte humana forma parte de la urdimbre biológica, racional, afectiva, ética y conductual tanto en su dimensión individual como social. Un exceso de sufrimiento puede generar emociones negativas que lleven a la razón a querer erradicar este sentimiento a través de la acción (*physis->pathos->logos->ethos*[35]) pero de *physis* a *ethos* se despliega todo un abanico cultural y sociológico que permite modular distintas respuestas posibles mediadas por el cambio de las mentalidades, actitudes y manifestaciones, en este en caso, en torno a la muerte, sufrimiento y sentido de la vida[36].

De una forma esquemática podría decirse que la reflexión filosófica en torno a la muerte puede situarse dentro de las coordenadas de physis (muerte biológica), pathos (actitudes), ethos (comportamiento) y logos (concepciones sobre la muerte). Partiendo de este esquema, en los siguientes apartados se

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[34] También es interesante esta cita de Le Breton (1999) "El dolor que sentimos no es, entonces, un simple flujo sensorial, sino una percepción que en principio plantea la pregunta de la relación entre el mundo del individuo y la experiencia acumulada en relación con él. No escapa a la condición antropológica de las otras percepciones. Es simultáneamente sopesada y evaluada, integrada en términos de significación y de valor. Va más allá de lo puramente fisiológico: da cuenta de lo simbólico" (p. 13).

[35] Este esquema conceptual al que se hace referencia para nombrar el orden de lo físico, de lo afectivo, de lo comportamental y de lo mental/intelectual (*physis, pathos, logos* y *ethos*), procede originalmente de Jacinto Choza (1991).

[36] Le Breton (1999). "Hacer del dolor un simple dato biológico es insuficiente en la medida en que su humanización es la condición necesaria para que se presente a la consciencia, y porque entre una realidad espacio temporal y otra, los hombres no sufren del mismo modo ni en el mismo momento" (p. 138).

profundizará, cuando sea conveniente, en cada uno de ellos tomando como punto de referencia el DAM.

7.2 De la muerte biológica a la muerte biográfica

7.2.1 La muerte como hecho biológico

En un primer nivel de reflexión, la muerte aparece como una realidad física y biológica. Siguiendo la terminología aristotélica, la muerte sería el momento del cese de la vida, el término de sus operaciones vitales y la pérdida de la unidad de un organismo como un todo (Aristóteles, 1987, 2003). Por eso, la muerte como fenómeno natural inscribe al ser humano en un proceso de destrucción y corrupción que le iguala a los demás seres vivos (Luper, 2014).

Desde un punto de vista médico, la muerte sigue siendo determinada por el cese de las actividades orgánicas aunque no existe consenso sobre el momento exacto en que se produce (Morin, 1994, p. 71). Un dato que ejemplifica este hecho es que, en la actualidad, existe únicamente un diagnóstico que se refiere al estar muerto y no al morir.

Son dos las posiciones en torno al momento exacto en que se produce la muerte biológica. Por un lado, los defensores de la muerte cerebral declaran que la muerte tiene lugar en el cese del funcionamiento del cerebro (neocórtex y sistema cerebral). Y por otro lado, otros autores sostienen que la muerte se da ante el cese del conjunto orgánico o biológico como una unidad funcional (cese de la actividad neuronal, fallo total e irreversible de las funciones del encéfalo, muerte del sistema nervioso como un todo (Arregui, 1994, p. 71; Schumacher, 2011). En todo caso, no deja de ser interesante observar que los debates en torno a la definición biológica de la muerte[37], al menos en los últimos 50 años, no pueden separarase del discurso sobre los avances científicos y la capacidad técnica de prolongar la vida a través de la donación y

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[37] El caso de la muerte es muy interesante, porque, a diferencia de otros fenómenos físicos o fisiológicos, su aspecto enigmático o misterioso se manifiesta ya a nivel biológico. Ni siquiera la "muerte biológica" es una evidencia. Hans Jonas, entre otros, polemizó con la idea de una muerte cerebral y le dedica un capítulo entero en su *Técnica, medicina y ética*. Agradezco este comentario al profesor Xavier Escribano.

trasplantes de órganos y a través de órdenes de resucitación[38]. Es decir, que la creación de nuevos escenarios en los que los límites de la vida se desdibujan, de alguna forma obliga a repensar qué es la vida y cuándo *acontece* la muerte. En este sentido, otro debate abierto no resuelto discurre en torno *quién* debe decidir sobre los límites de la vida y de la muerte. A partir de la década de los 60 el surgimiento de voces críticas hacia algunos abusos tecnológicos por parte de profesionales de la salud (ver p.e Potter, 1971) junto con el nacimiento de la bioética, propiciaron el cuestionamiento sobre si deben ser exclusivamente las disciplinas médicas las que establezcan los límites de la vida, antes que, por ejemplo, la bioética (filosofía) o la teología (Pernick, 1999, p. 9). Como puede verse, la dificultad que supone el estudio unilateral (en este caso meramente biológico) de una realidad compleja como lo es la muerte apunta hacia la necesidad de un diálogo multidisciplinar.

La comparación entre la muerte en el mundo animal y la muerte humana tal vez sea la que refleje mejor esta brecha que separa a unos y otros. Morin (1994), por ejemplo, sostuvo que la conciencia animal ante la muerte es explicada sobre todo como un instinto de toda la especie y no como una inteligencia de la muerte individual (cfr 1994, p. 58). De modo que la conciencia, que solo puede ser individual, supondría una ruptura entre la inteligencia específica e instintiva animal y la persona. Solo para el hombre, la muerte se presenta como un horizonte que encuadra su entera existencia y su forma de entenderla. En otras palabras: “la descripción del deceso humano en términos exclusivamente biológicos, resulta de todo punto insuficiente y es preciso considerarlo también desde la perspectiva biográfica, que es la específicamente humana” (Arregui, 1994, p. 184).

La muerte biológica solo puede ser concebida como ‘pura pasión’. Pasión, que deriva del griego *pathos*, podría traducirse por aquello que es padecido o sentido. La muerte como pasión sería como el sueño[39] que sobreviene y que no se puede controlar mediante la voluntad: acontece en la persona. Incluso, adelantando la cuestión sobre la muerte voluntaria, puede

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[38] Para un informe detallado sobre la definición de la muerte véase (Youngner et al., 1999).

[39] La comparación “muerte” – “sueño profundo” ha sido abordada por autores diversos. Por ejemplo, puede verse en Schumacher (2011, p. 8, 71, 122, 142, 144–7, 162, 208 y 217).

verse con claridad cómo la persona que quiere dejar de vivir tiene que recurrir a causas terceras para provocarse la muerte, incapaz, por su mera decisión, de ‘suprimir su vida biológica’. La imposibilidad de ser auténticamente agente de la propia muerte tendría que ver con que es la persona la que pone las condiciones para que algo le mate, pero el acto de morir(se) no está absolutamente en sus manos. Esto implica que mientras se está produciendo no puede ser revertido a voluntad: es el impacto de la bala lo que mata, no la acción de apretar el gatillo, es el choque contra el suelo el que produce la muerte de quien se ha lanzado desde un ático. Es por eso que, una vez se ha desencadenado el mecanismo que conducirá a la muerte, ya no se puede volver atrás por propia decisión. Sin embargo, volviendo al esquema inicial, se hace evidente la imposibilidad de plantear exclusivamente desde una perspectiva biológica (*physis)* el fenómeno de la muerte fuera de las demás dimensiones. El hombre, como diría Hölderlin es único en temer la muerte porque se “relaciona con ella” (citado en Arregui, 1994, p. 88). En el ser humano hay una anticipación, en mayor o menor medida, de su propia muerte que condiciona la forma de ver la vida, de asumir el sufrimiento, de programar sus proyectos vitales y de orientarla con un sentido.

7.2.2 La muerte como acto biográfico

> “Se podría afirmar que entre las especies animales vivas, la humana es la única para quien la muerte está omnipresente en el transcurso de la vida (aunque no sea más que en la fantasía); la única especie animal que rodea a la muerte de un ritual funerario complejo y cargado de simbolismo; la única especie animal que ha podido creer, y que a menudo cree en la supervivencia y renacimiento de los difuntos; en suma, la única para la cual la muerte biológica, hecho natural, se ve constantemente desbordada por la muerte como hecho de cultural” (Thomas, 1983, p. 11).

La muerte, según Heidegger (1951) –referencia indiscutible de la filosofía en torno a la muerte– es la posibilidad más radical (propia) de la existencia (cfr pp. 253–298). La muerte irrumpe las relaciones con el mundo, como fin de toda posibilidad y como aquella realidad insuperable. A diferencia de una visión metafísica (óntica) de la muerte que concebiría el deceso humano como el fin de la vida humana, Heidegger sostiene que la el ser humano es un *ser-para-la-*

muerte de forma que, la muerte, se presenta como su posibilidad definitoria y suprema, como aquella presencia que acompaña la vida del ser humano de la cual éste no se puede desprender. La visión heideggeriana (ontológica) en torno a la muerte, por tanto, podría concebirse desde el análisis de la estructura del ser y definiría el modo en el que el ser humano es: alguien que en su identidad más profunda está sellado por su condición mortal y tiende hacia su muerte.

El morir como acto biográfico, por lo tanto, significa que la muerte, no puede ser concebida como el fin de una serie de procesos biológicos, sino como el momento en el que se clausura la existencia individual de una persona, se descompone toda posibilidad de proyecto, se rompen "todos los vínculos en los que vivimos, nos movemos y somos, (precipitándonos) en una ausencia total de relación […] anulando la totalidad de nuestro enorme mundo subjetivo" (Thielicke, 1984, p. 41).

La conocida distinción de Heidegger entre *verenden* y *ableben* (1951, pp. 260–272) puede aportar luz sobre la distinción de la muerte biológica y la muerte biográfica. Mientras que el primer término haría referencia al cese sistemático de funciones vitales de un organismo (muerte biológica), la muerte para el *Dasein*[40] sería entendida como *ableben* (Haugeland, 2000, p. 66), es decir, el momento final y único para el *Dasein* a través del cual accedería a la muerte como tal. En este caso, la muerte es considerada como un fenómeno exclusivo del ser humano.

Morir para la persona implica cierto carácter de sorpresa e inadaptación. Es más, podría decirse que la conciencia anticipada de la muerte parece poner en cuestión al ser humano como animal prodigiosamente adaptado a cualquier medio. Siguiendo a Morin (1994) "la manifestación absoluta de la inadaptación de la persona a la realidad es la muerte. Aquel que no puede soportar la idea de la muerte muere por ello" (p. 79) de forma que el suicidio podría presentarse como la máxima expresión de esta inadaptación. Esta inadaptación tiene que

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[40] Ahondar sobre qué significa *Dasein* merecería un estudio detallado y concienzudo sobre la obra heideggeriana. De forma simplificada, y para no apartarnos de los objetivos de la tesis, aquí, *Dasein*, se podría traducir por ser humano. Para un estudio exhaustivo ver, por ejemplo, Colomer (1986), Wrathall y Malpas (2000), Carel (2006), etc.

ver con que, de alguna forma, la muerte se escapa del esquema que cualquier ser humano puede proyectar sobre su vida. Es difícil plantearse la realidad fuera de ese centro neurálgico que es el 'yo' bajo el que comprehendemos la realidad. Apartarse mentalmente de ese núcleo implicaría desplazarse a un cierto vacío, a una especie de 'vida sin mí' difícil de entender. De forma paralela, la inadaptación de la muerte tiene que ver con ese contraste entre un yo inconmensurable, que puede tener anhelos de inmortalidad, que querría tener una libertad absoluta y otro yo finito y mortal. La muerte, bajo esta perspectiva, no encajaría con las aspiraciones más profundas del ser humano: ser, querer, estar con los seres queridos para siempre. Es en este sentido que se genera la tensión entre la muerte que sería comprensible como hecho natural para quien tiene condición mortal, y la muerte como realidad repulsiva para el ser trascendente personal. De este modo, el suicidio puede presentarse como el rechazo de una realidad que no coincide con la vida que uno querría vivir al margen del sufrimiento, del dolor y de una muerte sobre la que no tenemos un control total.

La muerte como acto biográfico tiene un impacto sobre todas las áreas de la vida humana: afectiva, emocional, existencial, espiritual, etc. La conciencia de la muerte altera el mundo afectivo (*pathos*), genera un abanico de respuestas que da lugar a las distintas actitudes y posibilita que la persona desarrolle una conducta no fijada por la pauta instintiva de la naturaleza (*ethos*) (cfr Arregui, 1994). La persona humana es capaz de situar la muerte en algunas de estas coordenadas hasta el extremo de concebir una construcción racional a favor de la muerte voluntaria partiendo de la posibilidad individual de autodeterminar y tomar cierto control sobre el proceso y momento de morir (*logos*).

Las corrientes en pro de la eutanasia o del suicidio asistido son un ejemplo paradigmático de este planteamiento a favor del "derecho a elegir" la propia muerte. Incluso es frecuente identificar estas prácticas como actos de compasión y solidaridad que realizan tanto los familiares para evitar que su ser querido sufra, como los pacientes para evitar ser una carga para los demás (Callahan, 1992; Tuten, 2001). Si antes se ha definido la muerte biológica como pasiva, la muerte biográfica se caracterizaría por concebir la posibilidad de autodeterminación y de evitar todas las limitaciones –pasivas– que supone por ejemplo un proceso avanzado de enfermedad. En este contexto, la muerte voluntaria se plantea con frecuencia como una acción que liberaría al ser humano de este proceso de morir 'indigno' y como una acción moralmente aceptable fruto de una legítima autodeterminación (Ganzini et al., 2003; Kade, 2000; Quill, 1991; Sampaio, 1992; Van Brussel, 2014).

Si es posible autodeterminar la propia muerte, fuera del marco de las patologías psiquiátricas (*physis*), ha sido objeto de numerosos estudios y disputas (Améry, 1976; Andrés, 2016; Battin, 1995; Camus, 1985; Rehman-Sutter, Gudat y Ohnsorge, 2015). Hasta el momento, las voces predominantes han defendido que la mayoría de los suicidios tienen una causa fisiopatológica (Asociación Americana de Psiquiatría, 2014), mientras que una minoría ha sostenido que el ser humano es capaz de juzgar que es preferible la muerte a la vida y tomar las acciones necesarias para fenecer. Desde el punto de vista de la historia de la filosofía, el deseo de adelantar la muerte podría situarse, por un lado, en la tradición romántica e idealizada de la muerte y, por otro, en la tradición de la 'muerte voluntaria', expresión acuñada por Cicerón en *De Senectute,* que haría referencia a la libre autodeterminación racional de poner fin a la propia vida.

Ramón Andrés (2016) en su interesante ensayo sobre la historia de la muerte voluntaria en Occidente, refleja muy bien cómo el pensar en el suicidio exclusivamente como una enfermedad supondría caer en un cierto reduccionismo basado en entender la vida humana como una máquina organicista y reflejaría la incapacidad de atribuir la decisión a favor de la muerte voluntaria a una causa moral, espiritual o existencial:

> "Es erróneo pretender, como así lo sugiere una significativa parte de la medicina psiquiátrica de las últimas décadas, que el noventa por ciento de los suicidios cuenta con una base patológica. Sería inocente dar por buena esta propuesta. Aceptándolo, no haríamos más que evidenciar un tenue reconocimiento de nuestra condición, manifestar la ignorancia de la compleja trama de la realidad, de matiz incontable. Que el ser humano posea un nada desdeñable componente neurótico, evidente en su comportamiento desde la aurora de los tiempos, no significa que su existencia deba contemplarse bajo el estigma de la enfermedad. Se trata

> de una *conditio*, no de una patología. Pensar lo contrario, como bien señaló Karl Jaspers hace ya bastantes décadas, resultaría reduccionista e intelectualmente rudo […]: 'lo más sencillo parece ser admitir una enfermedad mental; en esto se ha ido tan lejos como en considerar loco a todo suicida. El problema del suicidio queda despachado poniéndolo fuera del mundo cuerdo. [...] El suicidio no es consecuencia de la enfermedad mental como la fiebre lo es de la infección'" (Jaspers, 1959, citado en Andrés, 2016, p. 11).

Asimismo, Margaret P. Battin, entre otros, en *Ethical issues in suicide* (1995), a pesar de posicionarse a favor de la muerte voluntaria (y racional), pone en duda que los actos humanos puedan llevarse a cabo de una forma completamente racional, al margen de las emociones o de las circunstancias. El punto de inflexión, sostiene Battin, no es el acto en sí −que la persona ponga fin a su vida−, sino que la acción haya sido tomada siguiendo un proceso lógico-racional. Para ello la autora define algunos supuestos bajo los cuales sería justificable la muerte voluntaria como acción respetable en una cultura o contexto social determinado (cfr 1995, pp. 132–135). En primer lugar, una condición *sine qua non* para legitimar esta decisión a favor de la muerte voluntaria es que fuera fruto de un discurso lógico y coherente desde sus premisas hasta sus conclusiones. En segundo lugar, esta decisión tendría que sostener una visión realista del mundo, de forma que se diera cierta adecuación entre el individuo y la realidad. En tercer lugar, la decisión tomada por la persona que quiera poner fin a su vida tendría que estar fundamentada en una información válida. En cuarto lugar, el suicidiosolo sería admitido si el objetivo fuera evitar el dolor. Y, por último, esta decisión a favor de la muerte voluntaria tendría que ir en la línea de respetar los valores fundamentales de la persona.

En el caso de las personas con enfermedades avanzadas –único caso que Battin arguye se escapa del tabú del suicidio y estaría más aceptado a nivel social–, estos indicadores son de especial interés. El respetar los valores fundamentales de la persona muchas veces es el argumento clave de las propuestas pro-eutanásicas o pro-suicidio asistido. El ya citado argumento de la autonomía, desde un discurso filosófico, también se ha relacionado con el concepto de autenticidad que, citando a Ferrara estaría vinculado a la idea de la “auto-coherencia de un todo simbólico y de la propia historia de vida” (1998, p. 70).

a) La muerte biográfica y el ideal de la autenticidad

La idea de la autenticidad del yo es próxima a la de realización personal, como el prototipo de artista romántico que es capaz de autodefinirse a través de su personalidad única (Ferrara, 1998; Taylor, 1994). Según esta concepción, se poseería quien fuera capaz de autorrealizarse, concepto contiguo al de autodeterminación y libertad.

Para Heidegger (1951, p. 331 y ss) la idea de autenticidad es central para comprender cómo este *ser-para-la-muerte* puede vivir su existencia autoposeyéndose. Según este autor, el ser humano tiene dos formas de vivir hacia la muerte (o *ser-para-la-muerte*): auténtica o inauténticamente. Vivir auténticamente significa asumir la condición finita y contingente del ser humano (Smoot, 1977; Zimmerman, 2000). Es precisamente esta identificación profunda con su condición, la expresión de que el ser humano ha alcanzado la máxima libertad. Por el contrario, la existencia inauténtica sería aquella en la que el *Dasein* huye de esta conciencia sobre la muerte y se deja llevar por el ruido de la vida ordinaria, se identifica con la masa anónima de personas que viven sin un proyecto propio.

Heidegger retoma la noción de posibilidad para definir el morir auténtico como la posibilidad distintiva del *Dasein*. La muerte es vista como “la posibilidad definitoria del ser humano” (Arregui, 1994, p. 24) que informa las demás posibilidades, haciéndolas finitas. En este sentido, el ser humano tiene cierta capacidad de apropiarse de su propia muerte en la medida en que la muerte es el momento final en el que, no solo se clausura, sino que se asume toda la existencia. Esta asunción de la existencia también denota *ser* de acuerdo a los fines propios de cada ser humano.

En algunos de los estudios sobre el suicidio asistido y la eutanasia este ideal de realización del yo aparece como una forma de reclamar el derecho a la autodeterminación (Ganzini et al., 2002, 2003). Con frecuencia, los procesos avanzados de enfermedad suponen un deterioro físico y psicológico, relacionado con malestar emocional y con una pérdida de control sobre la vida y circunstancias. Del mismo modo, las relaciones sociales se ven debilitadas y el ‘enfermo’, a causa de este contexto global, puede plantearse cuál es su identidad. Para estos pacientes, la actitud frente a la muerte voluntaria podría ser la respuesta al no querer perder la imagen que tienen de sí mismos ni a someterse a lo que va a suponer el proceso de enfermedad. En algunas investigaciones sobre la experiencia vivida al final de la vida, se constata el sufrimiento de quien observa el declive progresivo de sus capacidades y su pérdida de autonomía en relación a esta imagen propia (Chochinov et al., 2002; Lavery et al., 2001; Street y Kissane, 2001; Toombs, 2004). Por ejemplo, en un artículo de Thimothy Quill (2015) se describe el suicidio asistido como una forma de auto-preservación en lugar de auto-destrución. A través de los resultados mostrados en los estudios cualitativos de pacientes con enfermedades avanzadas, puede observarse que una experiencia común es la de la pérdida del yo, entendida como la percepción de desintegración de la propia esencia o identidad (“ya no soy la persona que era antes de la enfermedad”) (Charmaz, 1983, 1995; Lavery et al., 2001; Pearlman et al., 2005; Street y Kissane, 2001). De esta forma, el poder ejercer cierto control sobre las cincunstancias generaría cierto alivio para los pacientes y podría llegar a darse la paradoja de que quien quisiera morir lo haría precisamente para no perder esta identidad o dignidad que percibe como frágil y vulnerada y conseguir, así, mantener esta auto-afirmación (Kade, 2000; Quill, 1991).

En los movimientos a favor de ‘la muerte digna’, de entre los factores que indican los *morituri* como causa de su decisión, precisamente resaltan los que tienen que ver con aspectos vinculados a la cuestión de autoposesión ligada a la realización personal. Tal y como se plantea en los estudios antes citados (Ganzini et al., 2003; Kade, 2000; Quill, 1991), puede constatarse cómo la voluntad de morir está conectada con el ideal de ser fiel a uno mismo y concebirse como expresión libre de su autoposesión. El extremo de este planteamiento autodeterminista puede encontrarse en las “Celebraciones de los que mueren con valor” (*Celebration of Dying Bravely*) (Van Brussel, 2014) donde el que va a morir a través de la administración de los fármacos letales organiza su última fiesta y es elogiado como el héroe libre y valiente que es capaz de enfrentarse a su destino. En el estudio de revisión de las noticias publicadas en los medios de comunicación belga, Leen Van Brussel (2014) recoge algunos casos, a propósito de las muertes de Mario Verstraete, Hugo Claus, Marcel Engelborghs o Amelie Van Esbeen, que pueden ayudar a entender este fenómeno. Por ejemplo, ante el fallecimiento tras haber solicitado la eutanasia de Hugo Claus, artista mediático de Bélgica, se publicó el siguiente comentario en *De Morgen*, uno de los diarios más populares del país: "Él nos dejó en la forma que quería. Cuando fijó la fecha de su muerte, no dijo adiós sino que 'celebró' su adiós" (citado en Van Brussel, 2014, p. 184). Esta actitud en torno a la autolisis, ha sido identificada por algunos pensadores como fruto de la cultura narcisista. Jean Améry (1976), por ejemplo, que fue un defensor acérrimo de la muerte voluntaria, señala que "algunos afirman que el suicidio es una crisis de narcisista" (p. 114). Morin (1994) también lo dijo de una forma poética: "y esta es la razón por la cual tantas veces la muerte es un mal hijo de la ociosidad, el veneno del amor a sí mismo" (p. 64).

El ideal de la autenticidad también tiene que ver la antigua idea platónica que distinguía entre un yo propio, si se quiere, auténtico, que superaría la muerte; y otro impropio, que sería una cárcel y obstáculo para esta substancia inmortal. El testimonio de numerosos relatos de personas con enfermedades avanzadas hacen referencia a esta falta de identificación de su cuerpo con su yo y a la necesidad de superar esta brecha (Kleinman, 1988; Street y Kissane, 2001). Améry (1976) expresó este dualismo en términos de enajenación y no posesión del cuerpo enfermo que continúa siendo parte del yo:

> "cuando quisiéramos escapar de nuestra piel para huir del dolor, tal como lo formula una expresión corriente, nos resulta a la vez extraño y propio: la piel de la que nos queremos desembarazar, que queremos abandonar, sigue siendo nuestra, es parte integrante del Yo" (pp. 70–71).

La decisión de autodeterminar la muerte, se ve entonces, como la última forma de control sobre la vida, de realización, y como el triunfo de la libertad que ha conseguido, finalmente poseerse. Desde Rilke a Heidegger se ha propuesto la cuestión de la apropiación e interiorización de la muerte como fin de la existencia humana. No obstante, es cuestionable el hecho de que la muerte sea lo que realice el sentido de la vida y que en sí misma sea un fin en términos teleológicos. En tanto que el ser humano se plantea la muerte como un objetivo, queda implícita la idea de plenitud; pero no puede derivarse de aquí que, de hecho, la muerte conduzca a alcanzar ese yo inmortal autoposeído.

7.3 La anticipación de la muerte y la vivencia temporal de la mortalidad[41]

Una cuestión clave en la experiencia única del hombre frente a la muerte es que es capaz de anticiparla. Anticipar la muerte significa, entre otras cosas, que el ser humano tiene el "deseo de predecir [su] advenimiento; el deseo de protegerse de ella; el deseo de identificar los riesgos de su encuentro" y que desde esta perspectiva anticipatoria configura su vida de una forma particular (Kellehear, 2007, p. 17).

Para Heidegger, por ejemplo, el ejercicio de la anticipación de la muerte actualizaría al ser humano como *ser-para-la-muerte* haciéndole consciente de la muerte como posibilidad. De esta forma, mediante la reflexión anticipada de la muerte sentiría la angustia propia del *Dasein* que se dirige hacia la muerte con autenticidad y, apropiándose de la muerte, se haría libre. La cuestión sobre la anticipación del futuro en la vida humana, tiene que ver con su forma de experimentar la temporalidad. Toombs (1988, 1992), citando a Husserl, propone que el análisis de la conciencia revela una distinción radical entre el tiempo objetivo y el tiempo vivido. Mientras que el primero sería el tiempo entendido como *chronos*: mecánico, sucesivo, medible, cuantificable (sería el tiempo de los relojes, de los calendarios); el tiempo vivido sería *kairós*: el tiempo de la experiencia vivida, el tiempo cualitativo, subjetivo, personal. En este sentido, el tiempo como *chronos* no se podría anticipar como experiencia, en cambio como *kairós*, sí:

> "Los momentos de dolor… no siguen la secuencia ordenada y regular de los segundos y minutos que se marcan en la oscilación de un péndulo o

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[41] Este apartado fue presentado en la 1ª Jornada de fenomenología del cuerpo y análisis del dolor, organizadas por el Proyecto de Investigación "Fenomenología del cuerpo y análisis del dolor" (FIS 2013-43240P), en colaboración con la Facultad de Medicina y Ciencias de la Salud de la Universitat Internacional de Catalunya y SARX. Será publicado de forma ligeramente modificada en la revista *Health Aging and End of Life*.

> en el tictac de un reloj. El tiempo de un reloj es isotrópico. Los valores de su unidad son uniformes. El tiempo de cuando uno está enfermo es anisotrópico. Su valor varía con la intensidad del dolor, con la compañía del peso emocional, con la presión de los problemas…” (Schrag, 1982, p. 122 citado en Toombs, 1990, p. 232).

Tal como señalan algunos autores, la medicina moderna con frecuencia ha sobredimensionado la enfermedad como realidad exclusivamente objetiva y espacial (Toombs, 1990) de modo que podría correr el riesgo de desatender la parte vivencial de la enfermedad. Desde la fenomenología de la enfermedad se ha puesto el acento en una dimensión más subjetiva y experiencial, que entendería la enfermedad también desde esta dimensión temporal. El tiempo aquí sería definido como una secuencia interrumpida que abarcaría el presente, el pasado y el futuro de la persona. San Agustín, en su Libro X de las *Confesiones* estableció que el presente es la verdadera realidad temporal porque no puede darse un auténtico acceso ni al pasado ni al futuro fuera del presente. De este modo, la expresión correcta para referirse al pasado sería el “presente del pasado” y la correcta expresión para referirse al futuro el “presente del futuro”. Sartre (1993) desde una tradición totalmente distinta también sostuvo que “el único método posible para estudiar la temporalidad es abordarla como una totalidad que domina sus estructuras secundarias y les confiere su significación” (p. 139) resaltando la idea de que en la experiencia, el pasado, el presente y el futuro son una unidad inseparable que solo puede comprehenderse desde la globalidad. Bajo este marco conceptual, se entiende bien que la anticipación del dolor, la anticipación del futuro confiere un significado al presente.

La vivencia del tiempo comprendido cualitativamente permite a la persona viajar en su tiempo, proyectarse en el futuro y anticiparlo. Autores como Heidegger, Sartre, Bloch o Pieper han descrito a la persona como un ser que tiende al futuro y este futuro sería visto como el lugar de realización de los proyectos. Esta categoría de posibilidad, según Heidegger, sería la última y original determinación del ser humano. O dicho de otra forma podría entenderse el ser humano como alguien que, fundamentalmente, puede llegar a ser.

Con Heidegger y la noción de *ser-para-la muerte* el óbito humano también se circunscribe en la temporalidad entendida como una dimensión omniabarcante (1951, p. 260 y ss). El *Dasein*, que está abierto a la “infinita multiplicidad de posibilidades de la existencia” (Schumacher, 2011, p. 73), tiende hacia el futuro entendido como fin y marco de la realización. El futuro es comprendido no como el tiempo que habrá de llegar sino como el *locus* donde el *Dasein* alcanzará lo que potencialmente puede llegar a ser. La muerte, entonces, se presenta en un doble sentido como fin: como fin temporal de la vida (término) y como realización del ser en sentido teleológico.

Si entendemos a la persona como alguien abocado a un futuro que se presenta como el escenario de sus posibilidades, para las personas que padecen alguna enfermedad avanzada este escenario puede presentarse de forma dramática. Y concretamente la muerte y el dolor pueden aparecer como la interrupción irreversible de los proyectos futuros y como fin de toda posibilidad. Dicho de otra forma también podría decirse citando a Sundström (2001, p. 115) que “para un paciente con dolor, el pasado, así como el futuro es tragado o absorbido por el horrible hoyo del presente. Pero en la mayoría de los casos –donde el dolor severo no es omnipresente– el futuro, la anticipación individual y temida emerge como una realidad vitalmente importante”. Aquí se ve claro como no es el dolor presente lo que, muchas veces, lleva a pensar en el dolor futuro sino que es ‘la sombra del futuro dolor’ lo que es temido. Kay Toombs (2001) también lo expresa de una forma gráfica “el futuro (sería) como el horizonte del presente” (p. 3). Y este futuro en parte es construido desde el almacenamiento individual de experiencias que cada uno tiene y sobre el cual interpretamos la realidad (Toombs, 2001, p. 6).

Toombs recogiendo la tradición husserliana sobre esta cuestión, afirmando que el pasado y el futuro son los que proveen horizontes al presente, apunta a la posibilidad de anticipar un futuro que está por venir (cfr 1990, p. 229) y de anticipar un dolor futuro como parte de la experiencia presente (1990, p. 232). Asimismo, el futuro, a través de la conciencia dolorosa del presente, también podría perfilarse como un horizonte liberador en los casos en que fuera anticipado como libre de sufrimiento.

Volviendo la mirada a las experiencias relatadas en algunos estudios cualitativos con una población de final de vida, una realidad evidente es que su *hoy* está penetrado por el hecho de padecer una enfermedad. En estos pacientes destaca el hecho de tener poca esperanza de vida (menos de un año entre los que reciben tratamiento paliativo), la pérdida de funcionalidad física y de independencia se hacen acuciantes, se manifiesta un dolor que a veces es descrito como insoportable, prevalecen estados depresivos o desesperanzados (Breitbart et al., 2000; Dees et al., 2011) y aparece la percepción de pérdida del sentido de la dignidad, del sentido de la vida, pérdida de autonomía; junto con las subsiguientes consecuencias: dependencia, miedo a ser una carga para los demás, etc. (Chochinov et al., 2002; Chochinov et al., 2007; Guerrero-Torrelles et al. 2017; Kissane, Clarke y Street, 2001; Monforte-Royo et al., 2011; Vehling y Mehnert, 2014).

El DAM, tal y como fue definido en el estudio de consenso antes citado (Balaguer et al., 2016), es una reacción que tiene que ver con una situación de sufrimiento. La anticipación de la muerte es inseparable de la conciencia de un cierto deseo de que no se produzca. Sin embargo, puede darse una inversión de modo que se desee morir. Volviendo al esquema inicial, el DAM en este nivel, podría emplazarse en la esfera de *pathos* como una reacción psicológica, emocional y existencial en el contexto de una enfermedad que supone una amenaza para la vida.

Siguiendo con la definición de Balaguer et al. (2016), el DAM es una reacción a un sufrimiento por el cual el paciente no puede ver otra opción para acabar con éste que la muerte misma. Aquí el *pathos* sería encauzado a través de *logos,* que daría una valoración sobre la propia vida. En este punto puede verse especialmente la diferencia entre la anticipación de la muerte de forma cognoscitiva (conciencia de la muerte), la anticipación de la muerte en el sentido de desear que se produzca antes, y su consecución a través de la acción (poner fin a la vida de forma activa). Alguien puede desear morir y, sin embargo, no llevar a cabo ninguna acción por la cual termine con su vida; para llevar a cabo la acción es preciso que intervenga la voluntad. En consecuencia, entender que la expresión del DAM puede entrañar distintas intenciones, significados o consideraciones e implicar distintos modos de actuar es crucial para entender cómo este deseo es elaborado por la persona.

Desde la perspectiva de los estudios cualitativos sobre el DAM, una experiencia común es la alusión directa al miedo a un sufrimiento futuro imaginado. Por ejemplo en las siguientes citas escritas en un tiempo verbal futuro pueden servir para ver con claridad cómo esta proyección en el tiempo es fuente de angustia, temor y sufrimiento anticipado:

> “Ellos van a hacerse todo encima, van a tener que estirarse ahí y tener a alguien que les haga todo y van a sufrir todo el tiempo, ahí no hay felicidad, van a adelgazarse 60-70 libras, y se van a pasar sus últimas semanas de vida solo con dolor y agonía y la gente vendrá, la gente estará molesta, y ellos estarán molestos” (Lavery et al., 2001, p. 363).

O esta otra aporta el matiz de que el miedo es causado por la incertidumbre futura:

> “Nunca antes he estado en un hospital. No conozco lo que ahí sucede. Nunca he estado enfermo antes. He visto a otros pacientes gritando de dolor y ellos sufrieron… […] Solo escucharlos producía mucho dolor… Debe ser insoportable tener que gritar así…” (Mak y Elwyn, 2005, p. 345).
>
> O:
>
> “Va a ser extremadamente terrible […] las complicaciones y todo eso me provocarán mucho dolor y sufrimiento. Anticipo un futuro que será así. Muy grave, me da mucho miedo cuando pienso sobre esto” (Mak y Elwyn, 2005, p. 346).

También es interesante que en algunos estudios sobre las motivaciones que conducen a algunas personas a solicitar el suicidio asistido expliciten que, con frecuencia, esta petición de adelantar la muerte tiene que ver más con el miedo a un sufrimiento futuro que con un sufrimiento actual.

> “Tenía mucho miedo de cómo sería el final. Estaba preocupado por el dolor. Estaba preocupado por la falta de aire. Y sí, él tenía miedo de morir en la miseria” (Ganzini et al., 2003, p. 387).

Otras veces la anticipación del sufrimiento futuro estuvo determinada por la experiencia de personas cercanas a las que los pacientes de estos estudios cualitativos vieron sufrir (Chapple y Ziebland, 2006; Schroepfer, 2006). Volviendo a Toombs (2001), el “futuro es construido desde el almacenamiento de experiencias individual que cada uno tiene y sobre el cual interpretamos la realidad” (p. 6).

Finalmente, un último nivel de anticipación de la muerte serían la eutanasia y el suicidio asistido como formas en las que este sufrimiento físico, psicológico o existencial es encauzado por la voluntad y aniquilado a través de la acción. Como ya se ha mencionado anteriormente, aunque se podría pensar que el DAM implica la petición explícita de una práctica de muerte voluntaria, algunos estudios han demostrado que no es necesariamente así (Monforte-Royo et al., 2012) y que incluso puede haber niveles de intensidad en este deseo (Ohnsorge, Gudat y Rehman-Sutter, 2014a; Schroepfer, 2006). Aunque algunos autores hablan del deseo de morir como expresiones que podrían significar aceptar la muerte, deseo de ‘irse’, permitir a la enfermedad que siga su curso, moverse hacia otra realidad, estar cansado de vivir o suicidio racional (Nissim et al., 2009; Ohnsorge, Gudat y Rehman-Sutter, 2014b); desde la vivencia de los pacientes que expresan este deseo de morir, pueden observarse ciertas diferencias respecto a las del DAM cuando se hace en un contexto de enfermedad avanzada. De esta forma, como ya se ha dicho en el Capítulo 2, podría distinguirse el deseo de morir como un deseo general que abarcaría distintos grados de intencionalidad –por ejemplo desde pensamientos genéricos que no siempre se corresponden con un deseo real de acabar con la vida, con la petición de eutanasia–; del DAM como un deseo que se daría en el contexto particular del proceso de enfermedad. Mientras que el DAM podría abordarse clínicamente partiendo de las razones o motivos que lo originan; el deseo de morir, en algunos casos podría verse como la reacción natural (e incluso esperable) de quien se encuentra en las últimas semanas de vida. Por ejemplo, en los estudios de Nissim et al. (2009) y Ohnsorge, Gudat y Rehman-Sutter (2012) emergieron los temas de “aceptar la muerte” y de “dejarse ir”. En ambos casos, este “desear morir” estuvo relacionado con un deterioro progresivo y con un cierto “cansancio de seguir luchando” contra una muerte próxima e inevitable. Aunque es verdad que puede haber sufrimiento en la experiencia de final de vida, (el sufrimiento) no es incompatible –aunque parezca contradictorio– con aceptar la situación o con morir en paz.

7.3.1 La experiencia de la muerte, del morir y los sentidos del deseo de adelantar la muerte

Tal y como sostuvo Heidegger (cfr. 1951; cfr. Carel, 2006) el *Dasein* no puede experimentar su propia muerte. Esto significa que la experiencia personal sobre la propia muerte siempre se da desde la conciencia de la propia finitud o desde la experiencia agónica. Anatole Broyard en *Ebrio de enfermedad* (1990), trae a colación una cita del psicoanalista británico D.W. Winnicott en la que afirma: “He muerto […] Vamos a ver: ¿qué estaba ocurriendo cuando morí? Mi plegaria ha sido atendida. Estaba vivo cuando morí”. Esta falacia puede servir para iluminar la imposibilidad de vivir la propia muerte fuera de su anticipación.

Es interesante esta reflexión porque, desde la experiencia vivida de los pacientes que desean adelantar su muerte, se podría decir que no tienen un acceso directo a la muerte. La muerte no puede ser querida en sí porque no hay experiencia de ella, pero sí que se puede desear lo que supone la muerte para la vida, sobre todo, en tanto que dejar de sufrir. De este modo, si no hay un acceso directo a la muerte es lícito preguntarse si es verdaderamente la muerte lo que se desea cuando se expresa que se desea morir. La muerte, en su proyección sobre la existencia humana, puede ser aprehendida como el fin del sufrimiento y del dolor propio y ajeno, como el paso a una vida mejor, como la nada, etc.

Uno de los temas que emergió del análisis de los estudios cualitativos sobre el DAM fue la realidad de que muchos de los pacientes que expresan su DAM, lo hacen atribuyendo a esa expresión, no un DAM entendido de forma literal, sino un significado ulterior que tendría que ver con “lanzar un grito de ayuda”, “acabar con el sufrimiento”, “evitar el sufrimiento a los demás”, “controlar el proceso de morir” y “manifestar un deseo de vivir pero no de este modo”.

En este sentido es necesario recurrir a la fenomenología del deseo o de la voluntad para entender cuáles son las estructuras que dinamizan el DAM.

Alexander Pfänder en *Fenomenología de la voluntad* (2007, p. 31) sostiene que “un hecho de volición en sentido estricto lo tenemos en cambio, cuando no solo anhelamos, esperamos, apetecemos o, en suma, deseamos, sino que queremos cierta vivencia representada […] En cambio, algo puede ser muy bien objeto del deseo sin por ello ser querido”. En los pacientes que desean adelantar su muerte se ve muy bien cómo pueden atribuir distintos significados a estos deseos y no en todos los casos expresan que lo que quieren es la muerte como un fin en sí mismo. Dicho en otras palabras, podría decirse que aunque la muerte se presenta como el objeto del deseo, en algunos casos el significado subyacente a esta expresión revela que no necesariamente la muerte es lo que es querido.

Pfänder (2007) también sostiene que en la estructura del deseo se puede distinguir entre lo que es el deseo en sí respecto a la realización de lo deseado. En este sentido, como se ha dicho, la distinción entre considerar, tender hacia, decidir y ejecutar el deseo de morir puede marcar la diferencia entre el DAM como fenómeno clínico que surge como respuesta del sufrimiento relacionado con múltiples factores en el contexto de una enfermedad que amenaza la vida y la realización de prácticas como la eutanasia o el suicidio, que podría entenderse bajo el marco de deseo de morir tal y como se ha descrito antes. En este sentido, este autor también distingue entre representación y deseo. La representación podría entenderse como la acción de hacer presente a la conciencia una realidad concreta, sin embargo, este gesto no puede confundirse con el deseo de la cosa en sí. Un hombre puede pensar en la muerte como fin de su sufrimiento sin por ello desear realmente morir. A la representación debe unírsele el deseo, la volición. Entre la representación (concepción racional, intelectiva sobre el objeto del deseo en la conciencia) y el deseo (que se daría entre el ámbito de *physis* y *pathos*) se da la cultura, es decir, la construcción de un significado particular de acuerdo al micro-macro contexto en el que vive el individuo. “En la conciencia del deseo, lo que ante todo es objeto de la atención es más bien la representación de lo deseado” (Pfänder, 2007, p. 46). En el caso de los pacientes que desean adelantar la muerte, es muy importante partir de esta distinción entre deseo y representación para comprender la naturaleza compleja de este fenómeno. En los verbatims de los estudios cualitativos, la muerte fue representada principalmente como el fin de todo sufrimiento propio y ajeno o, en palabras de una paciente entrevistada en uno de los estudios sobre el DAM, “un vehículo para, para, detener mi vida” (Coyle y Sculco, 2004, p. 703). En este punto, es necesario recurrir a la antropología o historia de las mentalidades para identificar algunos elementos que contribuyen a la formación de la representación de la muerte en la cultura occidental contemporánea y entender cuál es el trasfondo que conecta la expresión del DAM con la realización de la muerte voluntaria.

7.4 La mediación cultural en la representación de la muerte contemporánea

> “Los hombres, según su condición social o su historia personal, no reaccionan de la misma manera frente a una herida o enfermedad idénticas; no tienen el mismo umbral de sensibilidad. No existe una actitud establecida en relación con el dolor, sino una probable, pero incierta, reveladora a veces de resistencias insospechadas, o a la inversa, de unas debilidades inesperadas, una actitud que también se modula según las circunstancias. La anatomía y la fisiología no bastan para explicar estas variaciones sociales, culturales, personales e incluso contextuales. La relación íntima con el dolor depende del significado que éste revista en el momento en que afecta al individuo. Al sentir sus horrores, éste no es el receptáculo pasivo de un órgano especializado que registra vaivenes impersonales de tipo fisiológico. La manera en que el hombre se apropia de la cultura, de unos valores que son los suyos, de su relación con el mundo, suponen un entramado decisivo para su aprehensión. Porque el dolor es, en primer lugar, un hecho situacional” (Le Breton, 1999, p. 9).

En esta cita de Le Breton puede verse el entramado complejo que componen las manifestaciones en torno al dolor. La vivencia del sufrimiento, el dolor, la enfermedad, la muerte, el duelo, etc. tienen una significación específica dependiendo del marco referencial que le proporciona cada cultura particular (Illich, 1976; Le Breton, 1999; Morris, 1991). Como hemos visto, la brecha que separa la muerte como realidad biológica y como realidad biográfica da pie a que se articulen multiplicidad de respuestas atendiendo a creencias y valores que pueden cambiar a lo largo del tiempo[42].

De esta forma, la anticipación de la muerte también se daría dentro de un marco de valores y creencias generando una serie de contestaciones individuales y colectivas que lógicamente influyen en la actitud del hombre ante la muerte. Dicho al revés, “la manera en que el morir y la muerte ocurren son también indicativas de la sociedad en la que vivimos” (Brotea, 2011, p. 5). En este sentido, sigue exponiendo Le Breton (1999):

> “El dolor que sentimos no es, entonces, un simple flujo sensorial, sino una percepción que en principio plantea la pregunta de la relación entre el mundo del individuo y la experiencia acumulada en relación con él. No escapa a la condición antropológica de las otras percepciones. Es simultáneamente sopesada y evaluada, integrada en términos de significación y de valor” (p. 13).

El hecho de que el sufrimiento de la persona dependa, parcialmente, de los contextos particulares supone que el DAM puede ser tamizado e interpretado a partir de los valores de las distintas sociedades.

7.4.1 El deseo de adelantar la muerte a propósito de la historia de las mentalidades

En los últimos años, numerosos autores han coincidido en que la actitud del hombre ante la muerte ha sufrido una transformación radical (Ariès, 1984, 2005; Arregui, 1994; Gorer, 1955). Durante siglos el hombre había vivido considerándose como creatura de Dios, como alguien que no dispone de su propia vida en su totalidad. Basta pensar en la condena social del suicida, en el planteamiento religioso de la muerte, en las batallas últimas de los enfermos medievales que se jugaban el destino eterno en la aceptación final de la voluntad divina. Tal y como describe Ariès (1984, 2005), en la Edad Media, la muerte ideal era aquella que permitía al moribundo y a su entorno social prepararse, tomar conciencia de la situación vivida: ‘se moría sabiendo que la muerte estaba llegando’ y, lo contrario, una muerte súbita, era vista como el

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[42] Para un análisis detallado del cambio de actitud de la muerte desde la Antigua Roma hasta nuestros días ver, por ejemplo, Ariés (1984, 2005).

peor de los castigos (“*a subitanea et improvisa morte libera nos Domine”*[43]). La presencia de una nueva actitud más o menos generalizada del hombre ante la muerte manifiesta un profundo cambio de mentalidad fundado en la emergencia de valores como el individualismo y la autonomía y la transformación de los horizontes morales y de sentido (Taylor, 1992, 1994, 2005).

La muerte inadvertida, tal y como denomina Ariès (2005) a la actitud contemporánea del hombre ante la muerte, sería aquella que ya no tiene un espacio social y no es representada por el imaginario colectivo. Se caracteriza por darse en un contexto hospitalario, frío, anónimo, donde la muerte es ocultada y la gente no quiere hablar de ella (Baudrillard, 1980; Kellehear, 2007). La muerte ha pasado a ser el tabú que antaño era el sexo (Gorer, 1955). Se da desde el anonimato y la trivialidad. Si antes la gente detenía su vida cotidiana para dejarse llevar por toda una serie de ritos funerarios y de duelo, actualmente, la muerte se ha convertido en un suceso sobre el que conviene no pensar y en la medida de lo permitido, hacer que altere lo menos posible la vida ordinaria.

En los países occidentales la representación social de estas realidades –cómo la sociedad las concibe y experimenta– está estrechamente relacionada con el nacimiento de la clínica moderna y con la medicalización.

Los avances de la técnica y el prestigio *in crescendo* de los médicos hicieron que, especialmente a partir de finales del siglo XIX, se diera un cambio de roles en el escenario de la enfermedad entre los médicos, enfermos y familiares particularmente (Ariès, 2005). Si hasta entonces, la enfermedad había formado parte de un proceso vital normalizado, asumido como algo propio de una naturaleza que en todo caso se encargaría de restablecer; la literatura posterior –como puede observarse de forma magistral en *La muerte de Iván Illich* (Tolstoi, 1995)– reflejó una nueva tendencia a recurrir al médico como el personaje sobre el que depende la vida del ser humano, como aquel que conoce el destino y es capaz de interceder a favor del enfermo. Dejó de ser el enfermo quien poseía el control sobre su enfermedad para cederlo a

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[43] Baste considerar esta invocación de la Letanía de los santos.

favor del médico e incluso de los familiares. Desde este momento, a menudo son estos últimos los que deciden por el enfermo e incluso guardan silencio sobre su diagnóstico.

La extensión de técnicas anestésicas, sobre todo a partir del siglo XX, supuso un hito en la historia de la medicina. A partir de entonces, se hizo posible el manejo del dolor y en cierto sentido el control de la enfermedad: “Por muchos triunfos que consiga la mente, por muchos dones que enriquezcan la humanidad, no habrá en el transcurso de los siglos una hora más dulce que aquella en que la esperanza, la duda y el temor contemplaron, en medio de profundo silencio, a un cerebro audaz decretar con voluntad casi divina la muerte del dolor” (Weir Mitchell citado en Martina M., s.f, p. 10).

Esta visión esperanzada sobre la vida humana ha propiciado que, en el caso de la civilización moderna, con frecuencia se dé una resistencia a aceptar la muerte y el dolor (Illich, 1976). En algunos estudios, se ha obsevado que algunas personas entienden la muerte como un accidente que la técnica en un futuro será capaz de evitar (cfr Arregui, 1994; Morin, 1994; Thomas, 1983) o como una enfermedad –la última– sobre la que llegará a intervenirse (Callahan, 1989), como un accidente que también requiere de intervención técnica. De esta forma se ha forjado –en expresión de Illich (1976, p. 52)– el mito del médico que lucha contra una muerte evitable en manos del poder curativo de la medicina.

La muerte hacia los años 1930 empezó a ser ‘desplazada’ al hospital (Ariès, 2005; Baudrillard, 1980). En el contexto de la medicalización este desplazamiento puede entenderse bajo dos formas: el traslado del cuidado y la extensión de la idea de ser una carga para los demás. La idea del traslado del cuidado tiene que ver con el traslado físico del moribundo al hospital (la muerte “ocurre” en el hospital). El acompañamiento del que muere pasó a ser vivida por los médicos en lugar de la familia o el sacerdote como había sido habitual en un pasado (Ariès, 2005; Walter, 1994). Este hecho supuso que los procesos de final de vida se circunscribieran a un contexto médico, tecnificado, salubre, ‘digno’, discreto, higiénico, privado (Walter, 1994, p. 59). La privación de la muerte como escenario doméstico también comportó para la familia una pérdida de los ritos y gestos del cuidado que durante siglos habían acompañado a los moribundos. El traslado del proceso de final de vida al hospital generó para los familiares y entorno social inmediato el desconocimiento de cómo tratar a sus enfermos. Así pues, la muerte no solo empezó a ser omitida sino que pasó a estar bajo el tabú de lo obsceno, sucio, de lo que conviene evitar (Gorer, 1955). Ariès (1984) también describe este proceso como un momento de mentiras donde enfermos, profesionales de la salud y familiares ocultan la presencia cada vez más cercana de la muerte a través de 'pactos de silencio' y hacer ver que en realidad la enfermedad no es tan grave: "se recubre la muerte [con] la enfermedad" (p. 471). El médico se convirtió en el nuevo maestro de ceremonias de este escenario, controlando el proceso de morir y privando al paciente de este momento a través de fármacos. Ariès describe esta nueva situación con una cita ilustrativa del jesuita F. de Dainville, cuando al ser intubado en una unidad de reanimación intensiva afirmó: "Me frustran en mi muerte" (Ariès, 1984, p. 471).

La identificación de estar enfermo con ser una carga para los demás se ha extendido como una de las imágenes más recurrentes de este imaginario social. A partir de Francis Bacon y Descartes la medicina empezó a presentarse como un medio a través del cual se podía combatir la muerte (Callahan, 1989; Le Breton, 1999). Este hecho supuso que progresivamente el proceso de morir dejara de ser visto como un hecho propio de la experiencia humana –que admite un acompañamiento cercano a través del cuidado– y se perdiera la posibilidad de atribuirle un sentido. De esta forma, la imposibilidad de responder bajo el lenguaje del cuidado ante el paciente enfermo junto a la pérdida de sentido de este acompañamiento, contribuiría a que la identidad del enfermo en la modernidad empezara a ser vista como pesada y molesta.

Paralelamente, mientras se pretenden alejar las fronteras del mundo de la muerte de la vida cotidiana, como señala Baudrillard (1980), el proceso de morir empieza antes con la estigmatización social, con la propia conciencia sobre el estar muerto para una sociedad que valora lo útil por encima de lo demás. Acogiendo el eslogan de Kellehear (2007) sobre la 'muerte social', podría decirse que uno empieza a morir en la enfermedad. La definición de muerte social es muy interesante porque sirve de marco para entender cómo algunas sociedades han desterrado a las personas que no son consideras dignas porque han perdido la autonomía, son una carga para los demás o ya no son productivas. La actitud individualista con la que se ha caracterizado estas sociedades (Taylor, 1994), también ha influido en esta nueva actitud sobre la muerte. La muerte, entonces, sería vista como una pérdida del yo (de la propia individualidad) y si, como hemos dicho, la muerte empieza en la enfermedad, la pérdida del yo también tendría lugar cuando el paciente recibe su diagnóstico. Es entonces cuando empezaría a dejar de vivir aunque lo deseara: “Deseo vivir pero no puedo vivir” (Mak y Elwyn, 2005, p. 345).

7.4.2 Muerte voluntaria y el deseo de adelantar la muerte en el contexto de la medicalización

La normalización de la eutanasia y del suicidio asistido, es decir, verlas como un derecho propio de la persona y como una práctica recurrente en las sociedades occidentales, reflejan bien este cambio de actitud respecto a la muerte. Algunos estudios han identificado que la muerte ideal sería la que se produce sin sufrimiento, sin que uno se dé cuenta de que se está muriendo (Emanuel y Emanuel, 1998; Sullivan, 2002; Vig y Pearlman, 2004). De hecho, numerosos estudios señalan que gran parte de la población de hoy tiene un fuerte afán por controlar el proceso de morir e incluso que el sufrimiento y el miedo al proceso de morir son más temidos que la muerte misma (Coyle y Sculco, 2004; Lavery et al., 2001; Pearlman et al., 2005; Thomas, 1983).

Tanto la eutanasia como el suicidio asistido son dos indicadores claros de cómo la construcción racional sobre la muerte puede generar nuevas actitudes frente a hechos naturales a través de la articulación de valores determinados. Estas prácticas, en tanto que inciden artificialmente en el proceso natural de la enfermedad, han sido vistas como una consecuencia de la medicalización. La intromisión de la técnica –en este caso a través la intervención médica y de fármacos letales– es la que hace posible que la persona que solicita morir, en efecto, muera por una causa tercera distinta a la de la evolución de su enfermedad.

En el caso de los estudios cualitativos sobre el DAM, a través de las narraciones obtenidas, puede reconstruirse un marco que ayude a entender cómo la medicalización puede mediar e incluso configurar la experiencia de este deseo. Como ya se ha dicho, para comprender la naturaleza del DAM es necesario recurrir a la biografía, creencias y valores de los pacientes. En este sentido, las expresiones de los pacientes se presentan como una fuente valiosa, no solo para profundizar en la naturaleza compleja del DAM, sino también para comprender los presupuestos, valoraciones y juicios que los pacientes tienen respecto a sí mismos, a su entorno social y a su situación.

De esta forma, en el cuarto artículo (Rodríguez-Prat y van Leeuwen, 2017) de esta tesis se analizaron todas los verbatims de los estudios cualitativos sobre el DAM –identificados previamente en el estudio de la actualización de la meta-etnografia sobre el DAM (Rodríguez-Prat, Balaguer, Booth y Monforte-Royo, 2017)– considerando cuatro presupuestos: 1. Presupuestos sobre el valor (moral) que se atribuyen los pacientes en términos de dignidad, autonomía y autenticidad 2. Presupuestos sobre las interacciones sociales en términos de cómo los demás atribuyen un valor al individuo (y a su vida) en el contexto de una enfermedad 3. Presupuestos sobre el valor de la vida 4. Presupuestos relacionados con la medicalización como marco contextual en el que el DAM es expresado.

Segunda parte:

Del marco teórico, a los estudios realizados

Capítulo 8. Preguntas de investigación y objetivos

Preguntas de investigación:

1. ¿Cómo es experimentada por las personas con enfermedades avanzadas la relación entre dignidad percibida, autonomía, control y autodeterminación?
2. El sentido de dignidad personal (cómo las personas perciben su propia dignidad), en personas con enfermedades avanzadas, ¿puede influir en la vivencia de su enfermedad y en su toma de decisiones?
3. ¿Qué aporta la fenomenología de la corporalidad y de la enfermedad en el análisis de los estudios cualitativos publicados en los que se establece la relación entre la dignidad percibida y la autonomía en pacientes con enfermedad avanzada?
4. ¿Cuál es la experiencia del deseo de adelantar la muerte expresado por personas con enfermedades avanzadas?
5. Los distintos contextos y marcos legales ¿pueden influir en la toma de decisiones de las personas que expresan el deseo de adelantar la muerte?
6. ¿Qué valores y presupuestos morales pueden identificarse en las narrativas de los participantes de los estudios cualitativos sobre el deseo de adelantar la muerte, desde el punto de vista de los pacientes, profesionales de la salud y familiares, considerando como marco contextual la medicalización?
7. ¿Puede considerarse la interrupción voluntaria de la hidratación y de la alimentación en personas con procesos avanzados de enfermedad, una expresión de deseo de adelantar la muerte?

Objetivos

Objetivo general:

1. Abordar los temas del deseo de adelantar la muerte, dignidad, autonomía o control en las personas con procesos avanzados de enfermedad desde la perspectiva de la literatura biomédica y filosófica (antropológica).

Objetivos específicos:

1. Efectuar una revisión sistemática y síntesis interpretativa (meta-etnografía) de los estudios cualitativos primarios sobre la relación entre dignidad percibida y autonomía en pacientes al final de la vida.

2. Analizar desde una perspectiva fenomenológica, particularmente desde las nociones filosóficas desarrolladas por Kay Toombs, la experiencia vivida de la dignidad percibida y autonomía a la luz de los estudios cualitativos publicados.

3. Realizar una revisión sistemática y síntesis interpretativa (meta-etnografía) de los estudios cualitativos primarios sobre la experiencia del deseo de adelantar la muerte desde la perspectiva de las personas con enfermedades avanzadas.

4. Analizar desde los datos aportados por los estudios cualitativos sobre el deseo de adelantar la muerte expresado por los pacientes, las posibles diferencias contextuales, atendiendo específicamente a la influencia que puede tener el hecho de que la eutanasia o el suicidio asistido estén despenalizados.

5. Examinar las nociones contemporáneas sobre la fenomenología y antropología de la enfermedad y del morir atendiendo particularmente a la medicalización y a los valores y presupuestos morales de los pacientes (familiares y profesionales de la salud) que expresan deseo de adelantar la muerte a la luz de los estudios cualitativos publicados sobre estefenómeno.

6. Comparar el fenómeno de la interrupción voluntaria de la hidratación y de la alimentación a la luz de los resultados de los estudios cualitativos sobre el deseo de adelantar la muerte.

Capítulo 9. Metodología

Esta tesis se presenta en la modalidad de compendio de publicaciones. Los artículos que forman parte de la tesis son:

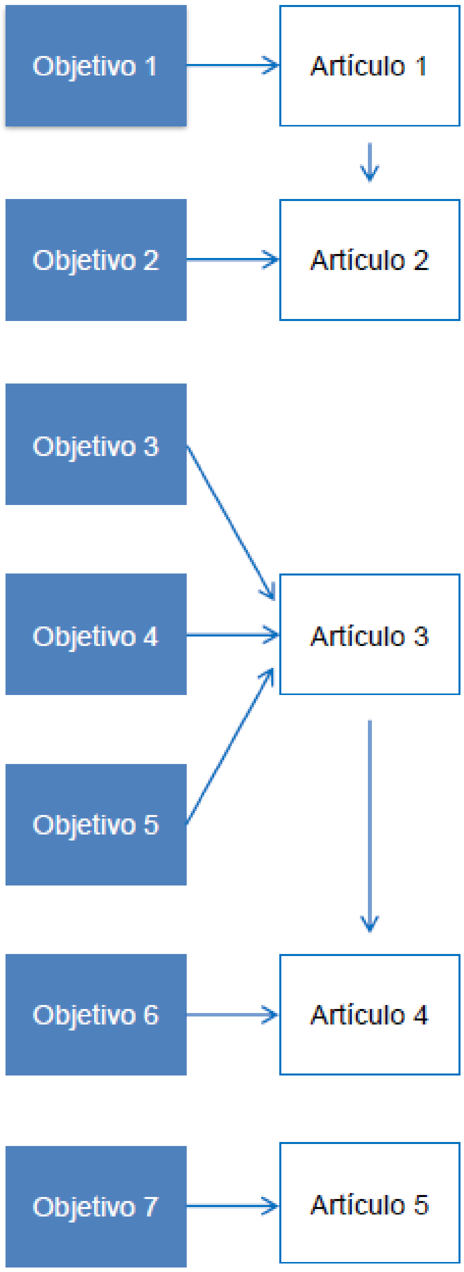
1. Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography
2. A philosophical view on the experiences of dignity and autonomy through the phenomenology of illness
3. Understanding new and old patients' experiences of the wish to hasten death: A systematic review and meta-ethnography
4. Assumptions and moral understanding of the wish to hasten death: a philosophical review of qualitative studies
5. Ethical challenges for an understanding of suffering: Voluntary stopping of eating and drinking and the wish to hasten death in advanced patients

En este apartado, se tratará de profundizar en algunos aspectos metodológicos en relación directa con los objetivos específicos de esta tesis.

Parte de lo que aquí se describe podrá encontrarse en el apartado de métodos de los artículos. Sin embargo, se tratará de ahondar en aquellos aspectos que en los manuscritos son tratados de forma tangencial o no son abordados.

En la figura 1 puede verse de forma esquemática la relación entre objetivos y estudios que se han llevado a cabo.

Figura 1. Organización de los objetivos y estudios de la tesis



Estudio 1:

Tal y como se ha descrito en el capítulo anterior, el primer objetivo de esta tesis fue efectuar una revisión sistemática y síntesis interpretativa (meta-etnografía) de los estudios cualitativos primarios sobre la relación entre dignidad percibida y autonomía en pacientes al final de la vida.

Para ello, se diseñó una estrategia de búsqueda con términos MeSH combinados con texto libre que se aplicó en Pubmed, Web of Science, CINAHL, PsycInfo y Cochrane Library, desde su inicio hasta el mes de julio de 2015.

Tras aplicar la estrategia de búsqueda a las diferentes bases de datos los estudios fueron seleccionados en tres fases teniendo en cuenta la pregunta de investigación y los criterios de inclusión. En primer lugar, se revisaron las 186 referencias seleccionadas por título, en segundo lugar, por abstract y finalmente por texto completo.

Se realizó una revisión sistemática y síntesis interpretativa siguiendo el método meta-etnográfico de Noblit y Hare (1988). Este método consiste en realizar, mediante un proceso inductivo, comparaciones constantes de los conceptos encontrados en los distintos estudios, con el fin de obtener una síntesis interpretativa. De acuerdo con los autores una meta-etnografía busca interpretar y comprender una realidad a partir de múltiples hechos, casos y narraciones. Así como examinar de forma crítica el fenómeno, comparando de forma sistemática estudios cualitativos para extraer conclusiones comunes (Noblit y Hare, 1988).

Se decidió optar por este método por dos motivos: por su amplio uso entre los investigadores; y por su capacidad de integración de estudios heterogéneos ya que no solo sintetiza los hallazgos sino que es capaz de resaltar las diferencias entre estos y generar una mayor comprensión del fenómeno.

Este último punto fue decisivo ya que se dio cierta heterogeneidad en los estudios incluidos y en sus objetivos particulares. La síntesis de los estudios cualitativos primarios no se focalizó en el total de datos y resultados, sino que planteó como objetivo explorar aquellos aspectos de los estudios que relacionaban la dignidad percibida con la autonomía y control (entre otros muchos que se manifestaron). La meta-etnografía de Noblit y Hare, en este sentido, parece ser la más flexible para poder realizar este tipo de síntesis.

Para la síntesis final de los 21 estudios se siguieron los siete pasos propuestos por los autores (Noblit y Hare, 1988). La primera y segunda etapas consistieron en definir el tema de investigación, concretar los criterios de inclusión, realizar la búsqueda sistemática y seleccionar los estudios. La pregunta de investigación que se estableció fue: ¿Cómo se percibe la relación entre dignidad y autonomía, control y autodeterminación al final de la vida? En la tercera etapa se llevó a cabo la lectura y relectura de los estudios incluidos hasta identificar los conceptos claves y secundarios en cada uno de ellos. Una vez obtenidos estas nociones principales, se utilizó el método de comparación de las traducciones recíprocas, que se refiere al proceso de examen de los conceptos clave en relación a otros conceptos dentro de cada estudio y entre los estudios.

El proceso de análisis y comparación se realizó por orden cronológico de publicación de los estudios incluidos, empezando por el más antiguo y analizando los conceptos clave.

En cuarto lugar, se determinó la relación entre los distintos estudios. Para ello se elaboró un cuadro donde se indicaron las categorías que emergieron de los estudios (nivel más descriptivo) y que sirvió como base para abstraer los temas y subtemas de todos ellos (niveles más abstractos que engloban las categorías halladas en los distintos estudios). La quinta fase consistió en traducir los estudios entre ellos. Es decir, en “deconstruir” los estudios, identificar distintas metáforas o conceptos partiendo de palabras o frases de los estudios originales. Este punto permitió comparar los distintos resultados y extrapolarlos a los de los otros estudios. En la sexta fase, se sintetizaron estas traducciones dando lugar a los distintos niveles de temas, subtemas y categorías finales. Por último, en la séptima fase, se expresó la síntesis de los estudios incluidos que dio lugar a una comprensión global del fenómeno de estudio y se presentó como respuesta a la pregunta de investigación establecida a priori.

Para reducir los sesgos fueron releídos los estudios incluidos y se llegó a un consenso en las categorías que emergieron entre los miembros del equipo investigador.

Estudio 2:

El segundo objetivo de esta tesis fue analizar desde una perspectiva fenomenológica, particularmente desde las nociones filosóficas desarrolladas por Kay Toombs, la experiencia vivida de la dignidad percibida y autonomía a la luz de los estudios cualitativos publicados.

Partiendo del estudio anterior, ‘Patient perspectives of dignity, autonomy and control at the end of life: systematic review and meta-ethnography’ (Rodríguez-Prat et al., 2016), fueron analizados algunos de los conceptos que emergieron, desde la fenomenología de la enfermedad y la corporalidad desarrollada por esta filósofa. Una de las razones por la cual se analizaron los conceptos identificados en la meta-etnografía a la luz de lo que esta autora ha trabajado, es porque Toombs tiene Esclerosis Múltiple y su filosofía parte de su experiencia como persona que vive con una enfermedad crónica de estas características. Es decir, su reflexión teórica va de la mano de su experiencia vivida, al igual que los pacientes con enfermedad avanzada analizados en el estudio realizado.

Los verbatims de este estudio proceden de estudios cualitativos primarios publicados en revistas científicas internacionales del ámbito biomédico, tal y como ya se ha descrito. Posteriormente, partiendo de las citas obtenidas en la revisión sistemática, seleccionamos de forma intencionada (*purposively)* aquellas que reflejaban mejor los conceptos desarrollados desde la óptica de la fenomenología de la corporalidad y enfermedad. Se utilizó la meta-etnografía realizada para mostrar cómo las narraciones de los propios pacientes, profesionales de la salud y familiares se comprenden mejor y pueden ser clasificados teóricamente a través de de una perspectiva fenomenológica.

En la fase analítica, como se ha explicado, se profundizó en las citas teniendo en cuenta los comentarios de los estudios primarios[44]. En este estudio, podría cuestionarse el problema de hacer depender el testimonio de terceras personas en argumentos fenomenológicos puesto que el acceso a los datos se dio a través de estudios primarios y podría cuestionarse si esta aproximación indirecta a la información permite un análisis fenomenológico ulterior. Sin embargo, esta limitación de índole metodológica, también podría plantearse en los estudios cualitativos primarios puesto que también se produce la misma situación al analizar o interpretar datos procedentes de estudios originales. Esta limitación estaría superada metodológicamente gracias a los procedimientos de rigor y a análisis que se llevaron

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[44] En este estudio, puede perderse en algún momento la visión de conjunto de todas las citas puesto que no fue posible mostrarlas todas debido al límite de extensión marcado por la revista en que se publicó el artículo. Para ver todas las citas de los estudios incluidos puede consultarse el material suplementario.

a cabo teniendo en cuenta las pautas propuestas por autores de referencia en síntesis cualitativa (Paterson et al., 2001; Pope, Mays y Popay, 2007; Sandelowski y Barroso, 2006). En este sentido, además, se trabajó meticulosamente a través de la triangulación de investigadores.

Asimismo, la descripción de la experiencia vivida por parte de Toombs, como enferma que padece esclerosis múltiple, en tanto que es una descripción fenomenológica, no trata únicamente de verbalizar una experiencia personal, meramente individual. La fenomenología es un arte de describir la experiencia, pero de una manera eidética, es decir, procurando desvelar estructuras universales, y en este sentido, transladables a otros individuos en situaciones vivenciales semejantes.

Las declaraciones de los pacientes vendrían a corroborar que la descripción fenomenológica de la corporalidad por parte de Toombs tiene una validez para esclarecer, comprender, interpretar esas múltiples experiencias. Toombs proporciona un análisis y bagaje conceptual apto para comprender con profundidad universal experiencias que parecen meramente individuales.

En ese sentido, la práctica clínica adquiriría un modelo conceptual −no meramente biográfico, o individual− para aproximarse a la experiencia vivida por parte de los pacientes. La experiencia no solo proporciona una vivencia inefable e incomunicable, sino que viene soportada por estructuras de sentido que pueden ser comprensibles e interpretables por otras personas, a partir de su descripción conceptual.

Estudio 3:

El tercer objetivo de esta tesis fue realizar una revisión sistemática y síntesis interpretativa (meta-etnografía) de los estudios cualitativos primarios sobre la experiencia del deseo de adelantar la muerte desde la perspectiva de las personas con enfermedades avanzadas.

A la luz de la nueva evidencia clínica sobre el DAM se diseñó una nueva estrategia de búsqueda que fuera más sensible y específica que la anterior. Se identificaron términos MeSH con texto libre que estuvieran directamente relacionados con la pregunta de investigación. La estrategia fue aplicada a Pubmed, CINAHL, Web of Science y PsycINFO.

De nuevo, se siguió el método meta-etnográfico propuesto por Noblit y Hare (1988) para la síntesis de los estudios. Sin embargo, como en este caso se trataba de una actualización de la literatura, se siguieron las guías propuestas por France et al. (2016).

El cuarto objetivo consistió en analizar desde los datos aportados por los estudios cualitativos sobre el deseo de adelantar la muerte expresado por los pacientes, las posibles diferencias contextuales, atendiendo específicamente a la influencia que puede tener el hecho de que la eutanasia o el suicidio asistido estén despenalizados.

En el proceso analítico se revisaron todas las citas de los participantes para identificar aquellos conceptos que explicaran el DAM desde la perspectiva de los pacientes. Para ello, se utilizó el *software* Atlas.ti 7 que sirvió para editar las citas y ordenar los códigos que fuimos generando a través de los sucesivos análisis (lectura y relectura de los estudios). A partir de aquí, se prestó especial atención a aquellos estudios donde la eutanasia o el suicidio asistido son legales como es el caso de Holanda y Suiza. Para ello se tuvieron en cuenta las narraciones de los participantes y otras referencias de los estudios primarios que pudieran hacer alusión a estas prácticas. Concretamente, en estos estudios se hizo explícito –a diferencia de los demás estudios- el hecho de que se había contactado con asociaciones o médicos a favor del Derecho a Morir (como *Dignitas* o *Exit* en Suiza) como medio para poner fin al sufrimiento.

Estudio 4:

El sexto objetivo fue examinar las nociones contemporáneas desde la fenomenología y antropología de la enfermedad y del morir atendiendo particularmente a la medicalización y a los valores y presupuestos morales de los pacientes (también desde la perspectiva de los familiares y profesionales de la salud) que expresan deseo de adelantar la muerte.

Partiendo de los verbatims que se habían seleccionado para la meta-etnografía sobre el DAM (Rodríguez-Prat et al., 2017), y tras obtener una explicación de la experiencia del DAM desde una perspectiva clínica, se observó que la mayoría de los verbatimstambién reflejaban valores y presupuestos que encajaban dentro de un marco referencial común.

Se elaboró una tabla con todas las citas de los pacientes, familiares y profesionales de la salud (a diferencia de la meta-etnografía en la que solo se incluyeron las citas de los pacientes) y se analizaron teniendo en cuenta los valores y presupuestos que reflejaban.

De esta forma, identificamos cuatro tipo de presupuestos que suelen mencionarse tanto en los discursos clínicos como ético-filosóficos en el contexto de final de vida; y que desde una perspectiva ética-filosófica pueden ayudar a entender con mayor profundidad la biografía de los pacientes.

Consideramos que unas coordenadas adecuadas desde las que analizar las expresiones verbales de los participantes podrían ser: la consideración que el individuo tiene de sí mismo a propósito de padecer una enfermedad; la consideración que el individuo tiene de sí mismo en relación a su trato con los demás; y, por último, la atribución de sentido y valor de la vida. En una fase analítica posterior, se identificaron algunos conceptos clave, valores y presupuestos morales para comprender estas coordenadas a la luz de las citas sobre el DAM: dignidad personal y social; autonomía y autenticidad; y, valor y sentido de la vida.

Estudio 5:

El último objetivo de esta tesis fue comparar el fenómeno de la interrupción voluntaria de la hidratación y de la alimentación a la luz de los resultados de los estudios cualitativos sobre el deseo de adelantar la muerte.

En este estudio comparamos los resultados obtenidos en la primera meta-etnografía publicada por nuestro grupo (Monforte-Royo et al., 2012)[45], con los

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[45] Este artículo se trata de un estudio de síntesis, con impacto en el mundo científico, ha sido muy citado en trabajos posteriores. Y al tratarse de un trabajo de síntesis, se ha constituído en obra referente a la hora de explicar el significado del DAM en pacientes avanzados (ver por ejemplo:

hallazgos obtenidos por el equipo de Bolt et al. (2015) sobre el VSED. Para ello analizamos los datos de los pacientes que habían fallecido por VSED del citado estudio, y nos preguntamos en qué medida los factores físicos, psicológicos, sociales, existenciales, demográficos podían estar relacionados con los identificados en la meta-etnografía original (Monforte-Royo et al., 2012).

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https://scholar.google.es/scholar?hl=es&q=what+lies+behind+the+wish+to+hasten+death&btnG=&lr= [Acceso 27 Abril 2017)).

Capítulo 10. Artículos publicados

Primer artículo: Patient perspectives of dignity, autonomy and control at the end of life: systematic review and meta-ethnography

Presentación del primer estudio de esta tesis:

En el año 2014 van Brussel publicó un artículo que tenía como objetivo analizar la contingencia de los conceptos de autonomía y de dignidad en el contexto de la toma de decisiones al final de la vida, partiendo de su descripción en los medios de comunicación belga, donde la eutanasia está despenalizada. En este estudio, se presentan los medios de comunicación como un espejo que refleja el discurso de una sociedad sobre un tema determinado y ”como uno de los canales claves en la difusión del material que permite a las personas entender y construir sus realidades sociales” (Van Brussel, 2014). Van Brussel describe y analiza casos de personas que murieron por eutanasia. En ellos puede verse la relación entre el discurso sobre la muerte digna y el ideal de la muerte como consecuencia de una elección autónoma y valiente, donde los *morituri* incluso celebran que van a morir. Por el contrario, el padecer una enfermedad incurable y sufrir sus consecuencias hasta el final, es descrito como algo vergonzoso e indigno. A raíz de estos casos se observa con claridad cómo la percepción de dignidad e identidad se presentan como conceptos análogos y que la pérdida de independencia y de autonomía es detectada como una amenaza para la dignidad.

En este artículo (Van Brussel, 2014), se describe la manifestación más radical de esta visión autónoma sobre la muerte a raíz de las artículos recogidos en prensa sobre las fiestas en las que se celebra la despedida de quien va a morir. En estas noticias se recogen las últimas palabras de personas mayores o con enfermedades avanzadas que quieren autodisponer de sí y darse muerte en el momento que ellos decidan: cuando la enfermedad todavía no les ha dejado en un estado de deterioro físico ni cognitivo, cuando todavía no padecen un sufrimiento insoportable.

En efecto, el modo en que las personas viven y conciben la enfermedad, el morir y la muerte ha cambiado de forma sustancial en las últimas décadas. De forma exponencial se ha extendido el ideal de la autonomía respecto a la vida y a la muerte, sin embargo, con frecuencia tanto desde la opinión pública como desde la teorización filosófica se hace referencia a conceptos que, sin duda tienen que ver con un ideal de plenitud humana, pero que en ocasiones están poco fundamentados en estudios empíricos o en las posibilidades clínicas de los pacientes que se encuentran al final de su vida. Ante declaraciones en las que se elogia a los que deciden quitarse la vida y se celebra la muerte voluntaria como manifestación de autonomía se pueden plantear muchas preguntas: ¿Es la muerte con dignidad sinónimo de muerte determinada? ¿Es ético y digno de la persona quitarse la propia vida? ¿Es indigno para la persona sufrir? ¿Pueden los valores personales influir en la toma de deciones de las personas en el contexto de final de vida? ¿Cuál es la experiencia vivida de las personas que se encuentran en estas circunstancias para que prefieran morir antes que seguir viviendo?

De esta forma, la motivación inicial del estudio realizado como parte de esta tesis, fue explorar cómo los pacientes que se encuentran al final de su vida perciben su propia dignidad en relación a la autonomía. Explorar con profundidad este binomio desde la experiencia vivida como algo previo a la construcción teórica y entender cuál es la realidad de los pacientes que se encuentran en estas circunstancias me parece el primer paso para poder diseñar planes de cuidado adecuados para cada persona y para promover un ‘cuidado con dignidad’ que atienda a la persona hasta el final de su vida.

Patient perspectives of dignity, autonomy and control at the end of life: systematic review and meta-ethnography

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RESEARCH ARTICLE

Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography

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Abstract

Background

Research in the end-of-life context has explored the sense of dignity experienced by patients with advanced disease, examining the factors associated with it. Whereas certain perspectives regard dignity as an intrinsic quality, independent of external factors, in the clinical setting it is generally equated with the person's sense of autonomy and control, and it appears to be related to patients' quality of life. This study aims to explore the relationship between perceived dignity, autonomy and sense of control in patients at the end of life.

Methods

We conducted a systematic review and meta-ethnography using reciprocal translation and line-of-argument synthesis. The search strategy used MeSH terms in combination with free-text searching of the Pubmed, Web of Science, CINAHL, PsycINFO and Cochrane databases, from their inception until 2015. This identified 186 articles, after excluding duplicates. The inclusion criterion was primary qualitative studies in which dignity, autonomy and control at the end of life were explored. Studies were evaluated using the CASP guidelines.

Results

Twenty-one studies recording the experiences of 400 participants were identified. Three themes emerged: a) dignity mediated by the loss of functionality, linked to the loss of control; b) dignity as identity; and c) autonomy as a determining factor of perceived dignity, understood as the desire for control over the dying process and the desire for self-determination. We propose an explanatory model which highlights that those patients with an intrinsic sense of dignity maintained a positive view of themselves in the face of their illness.

Conclusion

This synthesis illustrates how dignity and autonomy are intertwined and can be perceived as a multidimensional concept, one that is close to the notion of personal identity. The ability

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Conclusion: This synthesis illustrates how dignity and autonomy are intertwined and can be perceived as a multidimensional concept, one that is close to the notion of personal identity.

The ability to regard dignity as an intrinsic quality has a positive impact on patients, and the design of care strategies should take this into account.

Introduction

Safeguarding the dignity of patients at the end of life (EOL) has become a key objective of clinical practice [1–4]. Numerous studies have sought to clarify what is meant by dignity [4–11], to identify the variables associated with it [12–15], to examine how it is perceived by patients, families, and professionals [2,15–18], and to explore ways of assessing and enhancing it [20–22].

Broadly speaking, there are two ways in which the notion of dignity is evoked [6,7,23]. One is to consider it as something intrinsic and ontological, what some authors refer to as *basic dignity*. From this point of view, dignity is an irrevocable feature of personhood that does not depend on, or vary, according to circumstances. The second perspective refers to what is called *dynamic dignity*, that is, a personal quality that is related to people's perception of themselves and of the context in which they live. In the present study, dignity is considered to be a fundamentally intrinsic feature of the human individual [11], although it is acknowledged that what it entails in practice will depend on how patients see themselves and are seen by others, and also on how the nature of the illness in question affects the person's life and identity.

In the EOL context, another key issue is how the perception of dignity is mediated by the person's sense of autonomy or control. Although the two terms (autonomy and dignity) are sometimes regarded as distinct concepts, this is not always the case in the EOL setting. Indeed, a loss of autonomy or control among patients is often interpreted as a loss of self, and of the sense of dignity [24].

Research conducted to date on the perception of dignity and autonomy has contributed to an understanding of the needs and concerns of patients facing the EOL, and of the kind of care they require in order to improve their wellbeing. However, although the terms autonomy and dignity are frequently used in the literature [25] the link between them remains ambiguous. Paradoxically, dignity — especially when it is understood as autonomy — often appears as a key argument in clinical, legal, and philosophical debates, where it may be invoked to support opposing positions. A clear example of this is how the notion of dignity may be used both to support and challenge the act of euthanasia and assisted suicide, with opposing conclusions being reached on the basis of the same principles [23].

Given the lack of clarity and consensus that has been highlighted by many authors [2,4,5,9,23] the aim of this study was to explore, by means of a systematic review and interpretative synthesis, the primary qualitative studies that have focused on autonomy and control as mediators of the patient's dignity at the EOL, as perceived by patients, families and health professionals. The goal in doing so was to analyse how the relationship between autonomy and dignity is interpreted in this context.

Methods

The search strategy combined MeSH terms with free-text searching and was applied to Pubmed, Web of Science, CINAHL, PsycINFO and the Cochrane Library, from their start date until November 2015. Several trials were required to achieve a sensitive and specific search strategy (see Table 1). The reference lists of the retrieved studies were also reviewed.

Table 1. Final search terms for the strategy applied in the databases.

Patient	1 2 3	Patient [MeSH] Disease [MeSH] Illness [MeSH]
	4	1 or 2 or 3
End of life	5 6 7 8	Death [MeSH] Palliative [Text Word] End of life [Text Word] Hospice [MeSH]
	9	5 or 6 or 7 or 8
Die with dignity	10 11 12 13	Dignity [Text Word] Dignified dying [Text Word] Dignified death [Text Word] Die with dignity [Text Word]
	14	10 or 11 or 12 or 13
Autonomy	15 16 17	Control [MeSH] Autonomy [MeSH] Self-determination [MeSH]
	18	15 or 16 or 17
Final strategy	19	4 and 9 and 14 and 18

The inclusion criteria were as follows: primary qualitative studies in which dignity, autonomy and control at the end of life were explored (patients with an advanced disease and older people), as perceived by patients themselves, by their relatives and/or by health professionals. Studies involving paediatric samples were excluded. A total of 21 studies were included in the systematic review. Figure 1 shows the process of study selection.

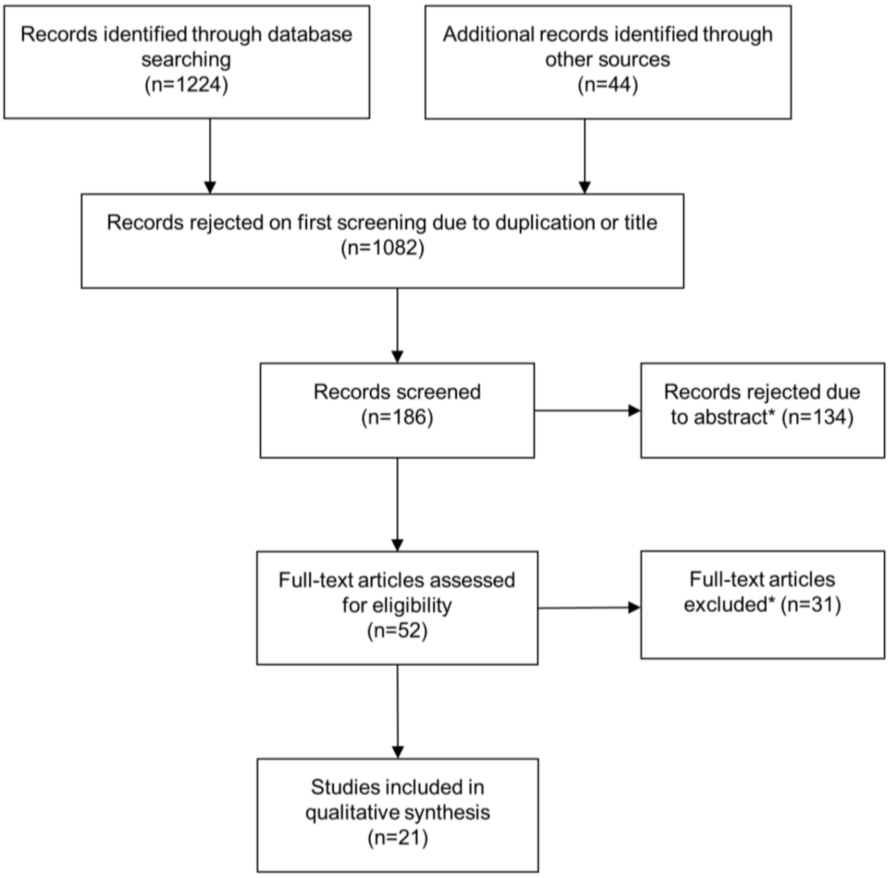

Fig 1. Flowchart of search results. *Studies excluded because of method, participants or topic.

A systematic review and interpretative synthesis was performed using the meta-ethnography approach developed by Noblit and Hare [26], This is an inductive method that involves making constant comparisons of the concepts found in different qualitative studies in order to enable a critical examination of a phenomenon and to extract common conclusions [26].

This study did not require ethical approval. Each of the included studies had been approved by the corresponding local ethics committee.

Quality Assessment

The studies included were evaluated using the CASP guidelines for qualitative research (see S1 Table) [27], with the exception of three reports [28–30], whose design was not compatible with these guidelines. However, we considered that all the studies could contribute to an understanding of the phenomenon, and consequently none of the reports was excluded due to its quality [31,32].

Findings

Description of the Studies Included

The studies selected had been conducted in the USA [24,28,33–37], Canada [2,30,38,39], Sweden [40,41], the UK [16,42,43], China [44–46] and Austria [17]. Fifteen of the 21 studies dealt exclusively with patients [2,17,24,28,29,35,37–42,44–46], three exclusively with health professionals [33,34,36], and three considered the views of patients, health professionals and family members (see Table 2) [16,30,43].

Table 2. Description of studies included in the review

Author(s)	Participants	Geographical location	Setting
Quill [28]	Patient with acute myelomonocytic leukaemia requesting physician-assisted suicide	New York, USA	Not specified
Bolmsjö [40]	Ten terminally-ill patients diagnosed with advanced cancer	Lund, Sweden	Lund University Hospital and a Lydiagarden centre for rehabilitation of cancer patients
Kade [29]	Patient with non-Hodgkin lymphoma requesting physician-assisted suicide	Not specified	Not specified
Mesler and Miller [33]	Thirty-five nurses, 9 social workers, 5 bereavement and/or volunteer coordinators, 3 nurse assistants, three executive directors, two chaplains, 1 regional manager, 1 medical director, and 1 physical therapist	USA	12 hospices
Lavery et al. [38]	Thirty-one men and 1 woman with HIV-1 or AIDS	Ontario, Canada	HIV Ontario Observational Database (HOOD), a provincial epidemiological database
Chochinov [30]	Patient with lung cancer with metastases to the liver, brain and adrenal glands.	Manitoba, Canada	Not specified
Chochinov et al. [2]	Twenty-three men and 27 women with terminal cancer	Manitoba, Canada	Urban extended care hospital housing a specialized unit for palliative care
Enes [16]	Eight terminally-ill patients (4 women and 4 men), 7 HPs (3 nurses, 1 doctor, 1 social worker, 1 chaplain and 1 physiotherapist) and 6 relatives (4 women and 2 men)	Surrey, UK	Hospice inpatient unit
Ganzini et al. [34]	Thirty-five physicians (8 women and 27 men)	Oregon, USA	Not specified
Coyle and Sculco [35]	Seven terminally-ill patients with cancer who had expressed a desire for hastened death	New York, USA	Urban cancer research centre
Volker et al. [36]	Nine oncology advanced practice nurses (from 39 to 55 years old)	Texas, USA	Members of the Oncology Nursing Society
Volker et al. [37]	Seven people with advanced cancer diagnoses	Texas, USA	Recruited via oncology advanced practice nurses
Mak and Elwyin [44]	Six advanced cancer patients who desired euthanasia while receiving palliative care.	Hong Kong, China	Unit followed the UK model of multi-disciplinary team palliative care with a multi-disciplinary team

Pearlman et al. [24]	Thirty-five patients who pursue a hastened death	Washington, USA	Patient advocacy organizations that counsel persons interested in PAS, hospices and grief counsellors
Chapple et al. [42]	Eighteen patients with terminal illness who discuss euthanasia and physician-assisted suicide	Oxford, UK	Interviews were contributions to the website DIPEX (Personal Experiences of Health and Illness; www.dipex.org)
Franklin et al. [41]	Twelve people aged over 85 years (10 women and 2 men)	Orebro, Sweden	Not specified
Pleschberger [17]	Twenty residents of nursing homes	Vienna, Austria	Not specified
Nissim et al. [39]	Twenty-seven ambulatory patients aged 45-82 years with advanced lung or gastrointestinal cancer	Toronto, Canada	Outpatient clinics at a large cancer centre
Brown et al. [43]	Fourteen clinical nurses, 3 general practice nurses, 8 patients with a diagnosis of a life-threatening illness and 5 carer	Scotland, UK	Not specified
Ho et al. [45]	Sixteen older Chinese palliative care patients with terminal cancer	Hong Kong, China	Terminal cancer patients receiving palliative care services in a major public hospital in Hong Kong
Ho et al. [46]	Eight men and 10 women (aged 44 to 92 years) diagnosed with stage IV cancer, with a life expectancy of no more than six months, living in the community either at home or in a long-term-care institution	Hong Kong, China	Patients enrolled in the out-patient palliative care programme of a major public hospital

Overview of Themes

Three broad themes emerged from the synthesis of studies. The first theme was dignity mediated by the loss of functionality linked to the loss of control and of the value ascribed to one’s life. The second theme was dignity as identity, specifically in relation to self-identity and the impact of social factors. Finally, autonomy as the basis of dignity was understood as the desire for control over the dying process and the desire for self-determination. Table 3 indicates the presence of these themes in each of the studies, while Table 4 presents some quotations that represent each theme.

Table 3. Themes, subthemes and categories identified in each study

Themes	Subthemes	Categories	Quill [28]	Bolmsjö [40]	Kade [29]	Mesler and Miller [33]	Lavery et al. [38]	Chochinov [30]	Chochinov et al. [2]	Enes [16]	Ganzini et al. [34]	Coyle and Sculco [35]	Volker et al. [36]	Volker et al. [37]	Mak and Elwyin [44]	Pearlman et al. [24]	Chapple et al. [42]	Franklin et al. [41]	Pleschberger [17]	Nissim et al. [39]	Brown et al. [43]	Ho et al. [45]	Ho et al. [46]	TOTAL
Dignity mediated by the loss of functionality	Loss of control	Loss of bodily functions	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓			✓	✓	✓	✓		✓	✓	✓	18
		Daily activities and circumstances	✓		✓		✓	✓	✓	✓	✓		✓		✓	✓		✓			✓	✓		13
	Value of one’s own life	‘Life without dignity no longer being worthy of living’	✓		✓	✓	✓	✓			✓					✓	✓		✓					9
		Quality of life		✓	✓		✓	✓	✓		✓	✓			✓		✓					✓	✓	11
Dignity as identity	Self-Identity	Body image	✓	✓	✓		✓			✓	✓	✓	✓	✓		✓	✓	✓						12
		Loss of the self	✓				✓	✓		✓	✓	✓	✓	✓		✓								9
		Loss of self-worth			✓		✓	✓		✓				✓		✓								6
	Social factors	Dependent: being a burden	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	19
		Role						✓		✓	✓				✓	✓					✓	✓	✓	8
		Social identity: fear of being vulnerable		✓			✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓		✓		✓		14
Autonomy as a determining factor of perceived dignity	Desire for control over the dying process	Control over the body	✓		✓						✓						✓							4
		Control of pain	✓		✓						✓	✓	✓	✓	✓		✓			✓				9
		Fear of suffering	✓		✓						✓	✓		✓	✓	✓	✓			✓				9
		Loss of functions	✓	✓	✓						✓			✓			✓			✓				7
		Control over the manner of death	✓		✓	✓	✓				✓	✓	✓			✓	✓			✓				10
	Desire for self-determination	Independence: ‘do what I want’	✓		✓					✓	✓					✓	✓						✓	7
		Right to choose	✓		✓	✓					✓					✓	✓			✓				7
		Decision making	✓		✓	✓					✓						✓						✓	6

Table 4. Some quotations from participants in the primary studies that illustrate each theme

Theme: Dignity mediated by the loss of functionality	**Other related themes**
Subtheme: Loss of control	
"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 [sic] 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" [38].	Dependency Inability to perform daily living activities Loss of identity
"Well it's the same thing as living in your own home you know. You are your own person. And… and if anybody started telling me to do this do that you know, and you've got to be in bed at a certain time and you've got to have help being undressed and all that, I think… God Lord, that... would be the worst thing that could happen. That would really be losing dignity. I wouldn't have any then" [2].	Loss of independence
"To the most—the simplest things, and when they were gone, he didn't have a reason... So it wasn't just the diarrhoea or the lack of driving; it was just losing, like, his definition—what his sense of vitality was. And when that was gone, then he was ready" [24].	Loss of identity Loss of control
Subtheme: Value of one's own life	
"I recognized only later that my patient's goal was to be released from a life that had robbed her of her independence and dignity" [29].	Loss of control over one's circumstances
"You talk about dignity... I've decided what I aim to do [I always wear make-up anyway, which I can't do now], I'm going to make sure that I always have my make-up on; make sure everything is very clean, very tidy and my nails properly done..." [16].	Inner dignity Physical image
"He told me that if all you can look forward to is your next enema, and you don't even like that much, what is the point of living?" [34].	Loss of the value of life
Theme: Dignity as identity	
Subtheme: Self-Identity	
"You've become a bag of potatoes to be moved from 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" [38].	Loss of self-esteem Feeling of being useless Loss of the value of life
"I think to be calm is dignity. I've never been a calm person and I hate myself sometimes for that… I'm becoming more calm. I've control... To be in control of your emotions; that's dignity" [16].	Inner dignity
"When I lost my hearing people started to ignore me. They didn't treat me as a human being anymore and then when I lost my eyesight there was nothing left. I couldn't go anywhere and couldn't do anything. For example, I can't hold the telephone and it's impossible for me to put it back if no one helps me. My friends want me to contact them as well but I can't without asking the girls and they have so much to do and are in such a rush so I forget to ask when they are in here" [41].	Loss of social recognition Inability to perform daily living activities
Subtheme: Social factors	
Interviewer: "Would you feel that your dignity was taken away if your children needed to help you?" Participant: "Well, yes if I knew... I wouldn't want them to take on the burden of doing that. That I have to depend on people just to look after me, to wash me, to take me to the bathroom and to cleanse… clean me up... I know this happens but I wish it didn't happen to me" [2].	Dependency Fear of being a burden on others
"It's going to the loo... in privacy... with locks on the doors... and not leaving a mess in the loo... for other people to clean up. Em, trying not to make nasty smells... I know this sounds silly 'cos... Its dignity…" [16].	Independence Importance of privacy
"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" [24].	Dependency Loss of the self
"I don't want to be a burden to my family and I want to have a say in the kind of care that I receive… But life here is harsh. I have no say in what to eat or when to eat, and my life revolves around the working routine of staff members. I have to wake up and eat breakfast at five o'clock every morning because this is when the morning shift starts working" [45].	Fear of being a burden on others Loss of independence
Theme: Autonomy as a determining factor of perceived dignity	
Subtheme: Desire for control over the dying process	
Participant: "If I'm going to be rolling around in my own faeces because I have no control, then forget it." Interviewer: "Ok. Why—why is that such an important thing?" Participant: "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... Dignity is that I have control over my body, when, when, not, 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" [38].	Loss of identity Desire for self-determination
"The patient said, 'I don't want strangers in my house. I'm doing fine. My wife's taking care of me. I just don't want people there 24 hours a day telling me what to do. And so I have had people refuse hospice because their understanding is that hospice takes control of their personal lives. They are very afraid of people coming in and they don't want anybody to take over the role of their caretaker'" [36].	Desire for independence Importance of privacy

"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" [24].	Decision making
Subtheme: Desire for self-determination	
"So she was a control person. You know, we are talking big time control... You know, I am in charge here. She sort of self-directed her medical care... It was a control issue, not a pain issue...'I want to be in control of my destiny. I don't want to go out as, you know, incontinent, in pain, crying, you know tearful person. I want to go out with some dignity'" [34].	Loss of functionality Loss of the value of life Desire for self-determination
"She just felt this was not dignified at all for a woman who had been in control all of her life. And she knew the end was near anyway. And she said, 'I want to do it on my terms. I want to choose the place and time. I want my friends to be there. And I don't want to linger and dwindle and rot in front of myself'" [34].	Desire for control over the end-of-life process Desire for self-determination
"When I saw her she was very, very weak and very dehydrated. And again, I told her, I said, 'Gee, you're within a couple days probably of losing consciousness just from dehydration, and we could make sure that you just slept and did not suffer and it would just be a short time.' She had the 15-day wait and she had 4 days before the medicine could be prescribed. And I told her that I didn't think she would be able to do that unless she could solve the nausea and dehydration that she would last for 4 days consciously and to take the medicine. And she sort of struggled into a sitting position, asked her husband to get her a glass of water, and said, 'I'll get the fluids down somehow.' And sort of forced… See, this is the paradox, this is where you learn that lesson about the control issue—she actually reversed the natural process to prolong her suffering, in order to be in control, to push the button herself" [34]	Desire for control over the dying process Desire for self-determination

a) Dignity mediated by the loss of functionality

A key theme in the studies included was the perception of dignity being diminished due to a loss of functionality. In most of the studies this was reflected in the idea that the illness reduced control over one's body and over daily activities and circumstances. An emerging sub-theme here concerned the value that patients ascribed to their life, which was often expressed in terms of quality of life [2,29,30,34,35,38,40,42,44–46].

Loss of control

Loss of control emerged both in relation to bodily functions and to daily activities and circumstances. A loss of control over one's body (incontinence, loss of mobility, of cognitive functions, etc.) was a central feature in 18 of the studies [2,3,16,17,24,28–30,33,35,36,38,40,42,45,46]. Some patients stated that diminished functionality undermined their sense of dignity. Participants in many of the studies [2,15,22,26-28,34,36,39,41-43,45] described their inability to perform daily living activities, which was often related to feelings of hopelessness and of being useless.

Value of one’s own life

In 11 of the studies this loss of functionality was associated with a diminished quality of life, and it was interpreted as a loss of the value of life [2,17,24,28–30,33,34,42]. By contrast, in those cases where patients highlighted an inner dignity linked to personal or spiritual values, a positive sense of dignity was maintained in spite of the loss of autonomy or control [30,40,43]. Being aware of this inner dignity enabled patients to feel that life still had value and meaning despite their current circumstances. These personal values were expressed in terms of having a positive impact on family ties [46] or in the form of religious or spiritual beliefs [17,30].

b) Dignity as identity

The second main theme that emerged concerned dignity as identity. In some way, dignity was seen as part of the patient’s identity and as something that was undermined by the dependency and fragility produced by the illness. This theme emerged with two sub-themes: self-identity (how the person sees him/herself), and social factors related to how the person believed he or she was seen by others.

Self-identity

Self-identity was related to physical image, the loss of self-esteem, and the loss of the self. The latter involved the perception that one’s identity or personal essence had been lost. Participants in many interviews described how the inability to look after themselves led to this feeling of a loss of self. In one study [38], some of the participants described the loss of their sense of dignity as a kind of disintegration of the self. Enes [16] referred to this notion as *being human* and *maintaining the individual self*.

For many participants their physical deterioration led to changes in their body. This was seen as altering their identity and as breaking the link with the person they had been prior to the illness. Some participants identified the loss of autonomy with being seen as "*vegetables*" [38,40,44] or with being treated as objects of little value, like "a bag of potatoes to be moved from spot to spot, to be rushed back and forth from the hospital" [38].

Another feeling associated with the loss of the self, and in some cases with physical deterioration, involved a loss of self-esteem. This loss of self-esteem was in turn associated with a feeling of being useless, since patients felt they had lost their social role, as well as with an awareness of their own vulnerability and their inability to manage daily living activities [2,29,37,38,42].

Social factors

In all the studies the participants made reference to how their illness influenced their immediate social context. This concerned both the impact of their needing adequate care and attention, as well as how this affected their relationships and their perception of themselves.

In the majority of studies the idea of being a burden was related to the loss of social role, coupled with a feeling of being useless and a loss of the value of life. This occurred when the patient, who had previously occupied a certain role within the network of social relations, lost this status and felt that he or she was no longer seen as important or ceased to perform a set of functions due to the illness. Those patients who had occupied a key role within the family, who had once held a notable professional position or who had always valued their independence found it particularly difficult to have to depend on others and to lose their position of influence. Note, however, that in the study which Ho et al. [45] carried out in China, where a strong sense of the family unit still exists, this loss of social role led to a strengthening rather than an undermining of relations. The imminent death of a relative consolidated relationships within the family and was seen as an opportunity to pass on knowledge to younger generations.

A key issue in patients' awareness of their dependency was when they needed a professional or relative to help with personal hygiene, eating, getting dressed or using the toilet [2,40,41,44]. In such cases this help was seen as humiliating and as an intrusion into one's privacy. Some patients expressed their fear of becoming a financial burden on the family, and, especially, of requiring kinds of help that they would never have wished to need [2,16,30,38,42].

Relatives and patients stated that health professionals could influence the patient's perceived dignity through the care, empathy and attitude they showed [2,16,30]. The wife of a man receiving 'dignity therapy' [30] said that one objective for professionals should be "helping the patient to feel that he is still of value", and she said that her and her husband's dignity had been maintained as a result of the care they had received in the hospital. By contrast, in studies such as that by Pleschberger [17] or Pearlman et al. [24] some patients said that they had been treated like objects, highlighting how this had made them feel ashamed. In 18 studies, mention was made of the fear of being vulnerable and fragile in relation to one's surroundings, and this was related to seeing oneself as dependent or as an object of contempt [2,24,34,35,38,42]. Some patients referred to how upsetting it was to think that they would be remembered as being useless and incapable.

c) Autonomy as a determining factor of perceived dignity

The third theme encapsulated two situations: desire for control *over the dying process* and desire for *autonomy in the form of self-determination*. Initially, the loss of control over one's life and circumstances was linked to the loss of control over the body and basic functions [28,29,34,42], to the fear of suffering [24,28,29,34,37,39,42,44], and to control over how one would die. Subsequently, however, it was related to more inner aspects, that is, to the patient's self-perception and to the feeling that life like this was not worth living.

Desire for control over the dying process

A view shared by most participants was that their dignity had been diminished by the loss of control over their life and circumstances: physical functioning, pain, suffering and how they would die [2,3,16,17,24,28–30,33,35,36,38,40,42,45,46]. For many of these patients, the fact that they were no longer in charge of their own body was experienced as undermining their dignity and as stripping life of its value. Although a loss of physical functioning, for example, is a common occurrence among patients with advanced disease, the participants in the studies included emphasized a strong desire for control and autonomy. These patients expressed feelings of impotence and frustration associated with the awareness of their progressive and inevitable deterioration, with a suffering that seemed meaningless.

In some studies [28,42] the medical impossibility of controlling pain, the adverse effects of treatments such as chemotherapy [26], or the cognitive effects (delusions, personality changes, etc.) of certain drugs were equated with an 'undignified death'.

The fear of suffering emerged in response to uncertainty about the future and irreversible deterioration. This fear was associated with feelings of anguish and despair, as well as with the corresponding fear of making others suffer. In the majority of cases this fear of suffering manifested as the expectation that the future would bring unbearable physical, emotional or existential pain. In some studies this kind of response to expected suffering was related to a previous negative experience involving the death of a relative or friend. Upon recalling this pain and suffering some patients reacted with fear or resistance as they did not wish to go through the same process [24,35,44].

In a similar vein, in those studies that explored the desire or wish to hasten death or the motivations that led patients to request physician-assisted suicide or euthanasia, this wish was related to the perception of a future that would be worse than death itself [44]. In other words, death here is seen as a way of putting an end to suffering. For example, in the case studies of Quill [28] and Kade [29] both patients had requested assisted suicide and this decision was taken prior to their finally losing control over their body or experiencing unbearable pain. What stood out here was their fear of suffering and of the pain to come, and their belief that the dying process would be intolerable.

Desire for self-determination

The desire for self-determination can be regarded as a basic principle among those patients for whom the right to choose and to make their own decisions was of paramount importance. Two categories emerged here: the desire for independence, in the sense of ‘Do what I want’, and the right to decide.

Patients who defended the notion of self-determination were described as people showing a strong and independent character in the different areas of their lives [24,34]. Hence their desire to have control over how they die is regarded both by themselves and by the authors of the studies concerned as being a natural consequence of their character and of their approach to life. In other words, they do not wish their lives to be subject to external rules that restrict their freedom, or to be determined by aspects of their illness or the need for help from others [16,24,28,29,34,42,46].

Common to these patients was a belief in the right to choose how they would die and what treatments they would accept or refuse. Likewise, people who showed a strong desire for control appeared as active participants in the process of their medical care, and they were not prepared to accept paternalistic attitudes on the part of health staff. The possibility of a hastened death was seen as the ultimate opportunity for control and freedom that a patient could have [34,35,42]. Thus, being able to exercise this freedom was interpreted as a way of rising above one's circumstances, including — paradoxically — their imminent death.

Discussion

This systematic review and interpretative synthesis confirms, from a theoretical and empirical point of view, that patients' perceived dignity at the EOL is related to their sense of autonomy and ability to control physical functions and their immediate surroundings. The illness experience, the transformation of identity and the influence of the social context are aspects that have been referred to in numerous settings [46–53], and in this regard the present synthesis, which takes multiple factors into account, can help to clarify the different ways in which the concept of dignity has been used in relation to autonomy.

The first theme to emerge from our analysis, namely perceived dignity mediated by loss of functionality, is a constant feature in research on the illness experience. In the EOL context, and regardless of whether the specific focus of a study was perceived dignity and control, the wish to hasten death (WTHD) or attitudes towards physician-assisted suicide (PAS) and euthanasia, this theme was an inevitable starting point given that the experience of dignity is determined by the patient's illness. In studies such as those by Chochinov et al. [2], Volker et al. [37], Pearlman et al. [24], Brown et al. [43] and Ho et al. [45] the loss of functionality was expressed in terms of illness-related problems or experiences that have an impact on perceived dignity. In other studies the loss of functionality was expressed directly as 'disintegration' [38], 'loss of the self or essence'

[24,38] and ‘perception of suffering for self’ [44].

The second theme identified, namely dignity as identity, was defined in terms of self-identity and in relation to how patients perceived they were seen by others. Numerous authors have highlighted the impact that the physical transformation produced by illness can have on personhood [5,16,48–52]. Street and Kissane [5] stated that ‘dignity is embodied’ since individuals know themselves and are known through their corporality. Hence the illness experience can imply a separation between an individual’s sense of him or herself as a person and the ‘altered’ body that is no longer recognized as one’s own [50]. This phenomenon was referred to by Franklin et al. [41] as ‘the unrecognizable body’.

The question of identity is also linked to certain emotions such as self-esteem that involve an appraisal of oneself [2,16,24,29,37,38]. Another common emotion is the fear of ‘losing oneself’, that is, of ceasing to be the person that one once was and, therefore, of letting others down. Shame may also be felt as a result of the loss of privacy inherent to the need for help with daily activities, or due to the lack of control over oneself and one’s everyday life.

It should also be noted that the view of self cannot be separated from how the person feels that he or she is seen or treated by others. Chochinov et al. [2], as well as those studies that have applied his model of dignity, place particular emphasis on what is referred to as the ‘social dignity inventory’, which has to do with how the quality of interactions with others influences a person’s sense of dignity. In studies of the WTHD, euthanasia or PAS, patients often refer to the fear of making others suffer and regard the wish to end their own life as an altruistic gesture [35,53]. The category of ‘being a burden on others’ has also been highlighted by several studies, and at times is reinforced by patients’ fear of being seen as vulnerable or incapable by their loved ones. These ideas would likewise be related to the aforementioned ‘loss of self’. Interestingly, however, the EOL situation has also been understood as an opportunity to strengthen the sense of ‘connectedness and belonging’ with respect to close friends and relatives [16,24,44].

The final theme that emerged from our systematic review was autonomy as a determining factor of perceived dignity. In the literature on the WTHD, euthanasia and PAS, one repeatedly finds support for the idea of a ‘dignified death’, the premise being that a person’s dignity depends on his or her ability to maintain autonomy and control. A meta-ethnography of the WTHD [54] found that this wish arose “as a kind of control over one’s life”. In the present analysis, the sub-theme ‘desire for control over the dying process’ would be linked to this wish to maintain a degree of control over certain aspects of one’s life, which does not necessarily imply taking some kind of action to hasten death. However, the second sub-theme, ‘desire for self-determination’, would be directly related to an explicit wish and willingness to end one’s life.

Explanatory Model

This synthesis provides an explanatory model that integrates in a dynamic way the various themes explored in the study (see Fig 2). Based on this model, one could say that the experience of all the participants was shaped by their illness experience, the social context and the impact of illness on their personal identity.

At the most descriptive level of analysis (process of identifying categories) we found that the majority of patients related the perceived loss of dignity to various factors: ‘loss of bodily functions’ in the context of ‘daily activities and circumstances’; a diminished sense of the ‘value of one’s own life’; loss of ‘quality of life’; a transformation of ‘body image’; a ‘loss of the self and self-worth’; feeling ‘dependent’, ‘vulnerable’ or that one was ‘a burden’ in the social sphere. The perception of dignity was also influenced by a ‘fear of suffering’, especially in relation to the ‘desire for control over pain’, ‘over the body’ and ‘over the manner of death’, as well as a strong desire for independence, for the ‘right to choose’ and for a ‘decision-making’ capacity.

At the more interpretative level of analysis, however, there was a consensus among the research team that these categories could not be defined as isolated elements. Rather, and given that the person is a holistic being, these categories need to be considered from a more integrative perspective in which the physical experience of illness is inseparable from its influence both on personal identity and on others (i.e. on the social context). For example, the analysis suggests that perceived dependency is the primary mediator of a diminished sense of dignity. In this case, dependency cannot be understood in isolation from the impact of the illness (which is the root cause of this dependency), from the new care relationship that emerges in the patient’s immediate surroundings, or from the construction of a new identity that is determined by the illness and a new way of life marked by anxiety, frustration, fear and uncertainty, etc.

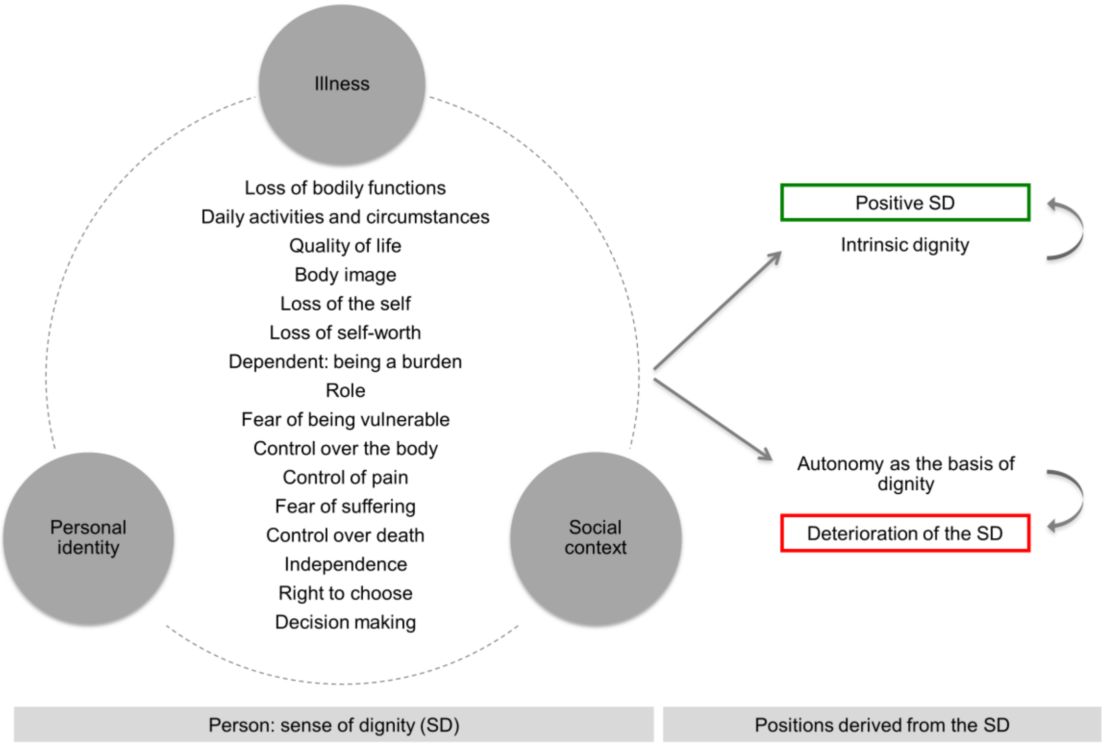

Fig 2. Explanatory model. This figure shows the dynamic integration and synthesis of the themes, subthemes and categories emerging from the lived experience of perceived dignity, autonomy and control.

Within this framework, two contrary positions can be observed. Those patients who emphasized the awareness of an internal or intrinsic sense of dignity maintained a positive view of themselves in the face of their illness [16,36,40,45] By contrast, patients whose sense of dignity was based on values such as autonomy, the ability to control their circumstances or quality of life found that their dignity was undermined [24,28,29,34,38,42].

One of the key themes to emerge from the present analysis concerned the desire for control over the dying process among patients whose sense of dignity was based on autonomy. Although there is some controversy regarding what motivates people to request euthanasia or assisted suicide, the results of this synthesis indicate that, when faced with a lack of control over pain, the inability to enjoy everyday life or the possibility of being a burden on others, then people with a strongly independent and ‘controlling’ nature are more likely to express a wish to hasten their death.

By using the methodology developed by Noblit and Hare [26] we were able to include a heterogeneous set of studies involving different methodologies, such that the final sample comprised 400 participants. In relation to the importance ascribed by Noblit and Hare to recognizing not just similarities but also points of difference, there was one concept that only featured in the study by Ho et al. [45], namely ‘transgenerational unity’. This category reflected the importance given in Chinese culture to the connection between different generations, this being regarded as part of spiritual unity within the family. The study by Brown et al. [43] was likewise the only study in which health professionals stated that when a patient or his/her relatives perceived a sense of burden, then this was the time to implement strategies aimed at increasing the patient’s independence and at providing the care needed to ensure that he or she felt well treated.

Limitations

One limitation of the present research is that although the majority of studies reviewed included people with advanced cancer, the final sample comprised participants with different symptoms and disease processes, and this may hamper the transferability of results. Furthermore, none of the studies included had the specific aim of describing the relationship between dignity and autonomy, and given the findings of Sandelowski et al. [55] this could reduce the frequency effect size. Another potential limitation is that although we designed a sensitive and specific search strategy, the subtlety with which the concepts defined by our search terms appear may have limited our findings in the databases used. Finally, mention should be made of the small number of countries in which the reviewed studies were conducted: the 21 studies included covered only six countries. With the exception of China, there may therefore be a degree of cultural homogeneity.

Implications for Practice

Given the intrinsic value of dignity, the fact that a person’s sense of dignity can be influenced by a range of external factors suggests that specific steps need to be taken to preserve it. The different therapies or models of dignity that have been developed to date illustrate the positive impact that these interventions can have on the individual concerned [2,43]. Clearly, these preventive or therapeutic measures must take into account the different aspects or areas of life on which a patient’s sense of dignity is based. In this regard, the results of this systematic review suggest that the loss of functionality coupled with dependency and the feeling of being a burden on others is one of the factors most likely to lead to a diminished sense of dignity. Consequently, anticipating possible frustration and empowering patients in those areas where they can make their own decisions and be more autonomous may prove to be beneficial.

The results of the review also suggest that health professionals need to be aware of the importance of taking into account the intrinsic or internal dignity of the people for whom they care. In fact, such awareness is important for caregivers, relatives, and even society as a whole, since on different levels they each can influence the extent to which an individual feels dignified or not. This way of seeing the other may favour the wellbeing and self-perception not only of the patient but also of the family members and professionals who are involved in his or her care. Consequently, there is a need to develop individualized treatment plans that foster this way of treating and caring for patients, and also to ensure that professionals receive adequate training in how to implement them.

Lines of Future Research

Given the influence of the family and social context, the various models of dignity that focus on the patient [2,3,43,56] could usefully be complemented by research into the strategies that family members could best implement in order to safeguard the perceived dignity of their loved ones. Likewise, although some quantitative research has examined patients' desire for control at the EOL, there are, to our knowledge, no studies exploring the experience and meaning attributed to this desire by patients themselves. A deeper understanding of this wish for control could help in the design of interventions to ameliorate this loss of self-identity or dignity in relation to autonomy and the WTHD.

Conclusion

Although dignity can be considered to be an intrinsic feature of human life, the results of this systematic review highlight how it is a complex, multifaceted and dynamic concept, one that is closely linked to the notion of personal identity. A more in-depth understanding of the experiential context of patients at the EOL may help to ensure that they are not reduced to their circumstances. Furthermore, given that the sense of dignity is readily influenced by a number of external factors, it is important to develop care plans that address the areas of life on which a patient's dignity is based, and thus contribute to an improved quality of life.

References

1. Casell E. The nature of suffering and the goals of medicine. N Engl J Med. 1982; 306: 639–645, DOI:10.1056/NEJM198203183061104.

2. Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. Soc Sci Med. 2002; 54: 433–443, DOI:10.1016/j.ejon.2011.07.010.

3. Östlund U, Brown H, Johnston B. Dignity conserving care at end-of-life: A narrative review. Eur J Oncol Nurs. 2012; 16: 353–367, DOI:10.1016/j.ejon.2011.07.010.

4. Guo Q, Jacelon CS. An integrative review of dignity in end-of-life care. Palliat Med. 2014; 28: 931–940, DOI:10.1177/0269216314528399.

5. Street AF, Kissane DW. Constructions of dignity in end-of-life care. J Palliat Care. 2001; 17: 93–101.

6. Ashcroft RE. Making sense of dignity. J Med Ethics. 2005; 31: 679–682, DOI:10.1136/jme.2004.011130.

7. Leung D. Granting death with dignity: patient, family and professional perspectives. Int J Palliat Nurs. 2007; 13: 170–174, DOI:10.12968/ijpn.2007.13.4.23487.

8. Pullman D. Death, dignity, and moral nonsense. J Palliat Care. 2004; 20: 171–178.

9. Johnson PR. An analysis of “dignity”. Theor Med Bioeth. 1998; 19: 337–352, DOI:10.1023/A:1009951813110.

10. Nordenfelt L. The varieties of dignity. Heal Care Anal. 2004; 12: 69–81.

11. Sulmasy DP. The varieties of human dignity: a logical and conceptual analysis. Med Health Care Philos. 2013; 16: 937–944, DOI:10.1007/s11019-012-9400-1.

12. Chochinov HM, Hassard T, Mcclement S, Hack T, Kristjanson LJ, Harlos M, et al. The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care. J Pain Symptom Manage. 2008; 36: 559–571, DOI:10.1016/j.jpainsymman.2007.12.018.

13. Hack TF, Chochinov HM, Hassard T, Kristjanson LJ, McClement S, Harlos M. Defining dignity in terminally ill cancer patients: A factor-analytic approach. Psycho-Oncology. 2004; 13: 700–708, DOI:10.1002/pon.786.

14. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity in the terminally ill: a cross-sectional, cohort study. Lancet. 2002; 360: 2026–2030, DOI:10.1016/S0140-6736(02)12022-8.

15. Vehling S, Mehnert A. Symptom burden, loss of dignity, and demoralization in patients with cancer: a mediation model. Psycho-Oncology. 2014; 23: 283–290, DOI: 10.1002/pon.3417.

16. Enes SPD. An exploration of dignity in palliative care. Palliat Med. 2003; 17: 263–269, DOI:10.1191/0269216303pm699oa.

17. Pleschberger S. Dignity and the challenge of dying in nursing homes: The residents' view. Age and Ageing. 2007; 36:197–202, DOI:10.1093/ageing/afl152.

18. Jacelon CS. The Dignity of Elders in an Acute Care Hospital. Qual Health Res. 2003; 13: 543–556, DOI:10.1177/1049732302250762.

19. Jacobson N. A taxonomy of dignity: a grounded theory study. BMC Int Health Hum Rights. 2009; 9: 3, DOI:10.1186/1472-698X-9-3.

20. Hall S, Edmonds P, Harding R, Chochinov H, Higginson IJ. Assessing the feasibility, acceptability and potential effectiveness of Dignity Therapy for people with advanced cancer referred to a hospital-based palliative care team: Study protocol. BMC Palliat Care 2009; 8: 5, DOI:10.1186/1472-684X-8-5.

21. Albers G, Pasman HRW, Rurup ML, Vet HCW De, Onwuteaka-Philipsen BD. Analysis of the construct of dignity and content validity of the patient dignity inventory. Health Qual Life Outcomes. 2011; 9: 45, DOI:10.1186/1477-7525-9-45.

22. Periyakoil VS, Stevens M, Kraemer H. Multicultural long-term care nurses' perceptions of factors influencing patient dignity at the end of life. J Am Geriatr Soc. 2013; 61: 440–446, DOI:10.1111/jgs.12145.

23. Pullman D. Dying with dignity and the death of dignity. Health Law J. 1996; 4: 197–219.

24. Pearlman RA, Hsu C, Starks H, Back AL, Gordon JR, Bharicha AJ et al. Motivations for physician-assisted suicide. J Gen Intern Med. 2005; 20: 234–239, DOI:10.1111/j.1525-1497.2005.40225.x.

25. Walsh K, Kowanko I. Nurses' and patients' perceptions of dignity. Int J Nurs Pract. 2002; 8: 143–51, DOI:10.1046/j.1440-172X.2002.00355.x.

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

27. CASP. Critical Appraisal Skills Programme. Ten questions to help youmake sense of qualitative research. Oxford; 1999. Available: http://media.wix.com/ugd/dded87_951541699e9edc71ce66c9bac4734c69.pdf.

28. Quill T. Death and dignity–A case of individual decision making. N Engl J Med. 1991; 324: 691–694, DOI:10.1056/NEJM199103073241010.

29. Kade W. Death with Dignity: A case study. Ann Intern Med. 2000; 132: 504–506.

30. Chochinov HM. Dignity-conserving care-a new model for palliative care: helping the patient feel valued. JAMA. 2002; 287: 2253–2260, DOI: 10.1001/jama.287.17.2253.

31. Sandelowski M, Barroso J. Focus on research methods: toward a metasynthesis of qualitative findings on motherhood in HIV-positive women. Res Nurs Health. 2003; 26: 153–170.

32. Dixon-Woods, M., Sutton A, Shaw R, Miller T, Smith J, Young B et al. Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods. J Heal Serv Res Policy. 2007; 12: 42–47, DOI:10.1258/135581907779497486.

33. Mesler A, Miller PJ. Hospice and assisted suicide: the structure and process of an inherent dilemma. Death Stud. 2000; 24: 135–155, DOI:10.1080/074811800200612.

34. Ganzini L, Dobscha SK, Heintz RT, Press N. Oregon physicians' perceptions of patients who request assisted suicide and their families. J Palliat Med. 2003; 6: 381–390, DOI:10.1089/109662103322144691.

35. 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, DOI:10.1188/04.ONF.699-709.

36. Volker DL, Kahn D, Penticuff JH. Patient control and end-of-life care part I: the advanced practice nurse perspective. Oncol Nurs Forum. 2004; 31: 945–953, DOI:10.1188/04.ONF.945-953.

37. Volker DL, Kahn D, Penticuff JH. Patient control and end-of-life care part II: the patient perspective. Oncol Nurs Forum. 2004; 31: 954–960, DOI:10.1188/04.ONF.954-960.

38. 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, DOI:10.1016/S0140-6736(01)05555-6.

39. 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: 165–171, DOI: 10.1016/j.socscimed.2009.04.021, DOI:10.1016/j.socscimed.2009.04.021.

40. Bolmsjö I. Existential issues in palliative care-interviews with cancer patients. J Palliat Care. 2000; 16: 20-24.

41. Franklin L, Ternestedt B, Nordenfelt L. Views on dingity of elderly nursing home residents. Nursing Ethics. 2006; 13: 130–146, DOI:10.1191/0969733006ne851oa.

42. Chapple A, Ziebland S. What people close to death say about euthanasia and assisted suicide: a qualitative study. J Med Ethics. 2006; 32: 706–710, DOI:10.1136/jme.2006.015883.

43. Brown H, Johnston B, Östlund U. Identifying care actions to conserve dignity in end-of-life care. Br J Community Nurs. 2011; 16: 238–245, DOI:10.12968/bjcn.2011.16.5.238.

44. Mak YYW, Elwyn G. Voices of the terminally ill: uncovering the meaning of desire for euthanasia. Palliat Med. 2005; 19: 343–350, DOI:10.1191/0269216305pm1019oa.

45. Ho AHY, Chan CLW, Leung PPY, Chochinov HM, Neimeyer RA, Pang SMC et al. Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong. Age and Ageing. 2013;42:455-461, DOI:10.1093/ageing/aft003.

46. Ho AHY, Leung PPY, Tse DMW, Pang SMC, Chochinov HM, Neimeyer RA et al. Dignity amidst liminality: healing within suffering among chinese terminal cancer patients. Death Stud. 2013; 37: 953–970, DOI:10.1080/07481187.2012.703078.

47. 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, DOI:10.1056/NEJMsa020562.

48. Charmaz K. Loss of self: a fundamental form of suffering in the chronically ill. Sociol Heal Illn. 1983; 5: 168–197, DOI:10.1111/1467-9566.ep10491512.

49. Kleinman A. The illness narratives: Suffering, healing, and the human condition. Basic Books; 1988.

50. Charmaz K. The Body, Identity, and Self. Sociol Q. 1995;36:657–680, DOI:10.1111/j.1533-8525.1995.tb00459.x.

51. Paterson BL. The shifting perspectives model of chronic illness. J Nurs Scholarsh. 2001; 33: 21–26.

52. Aujoulat I, Marcolongo R, Bonadiman L, Deccache A. Reconsidering patient empowerment in chronic illness: A critique of models of self-efficacy and bodily control. Soc Sci Med. 2008; 66: 1228–39, DOI:10.1016/j.socscimed.2007.11.034.

53. Compassion & Choices. Why Physicians & The American Public Health Association Support Death with Dignity. 2015. Available: https://www.compassionandchoices.org/userfiles/Why-Physicians-Support-Aid-In-Dying.pdf.

54. Monforte-Royo C, Villavicencio-Chávez C, Tomás-Sábado J, Mahtani-Chugani V, Balaguer A. What lies behind the wish to hasten death? A systematic review and meta-ethnography from the perspective of patients. PLoS One 2012;7:e37117, DOI:10.1371/journal.pone.0037117.

55. Sandelowski M, Barroso J, Voils CI. Using qualitative metasummary to synthesize qualitative and quantitative descriptive findings. Res Nurs Health. 2007; 30: 99–111, DOI:10.1002/nur.20176.

56. Li H-C, Richardson A, Speck P, Armes J. Conceptualizations of dignity at the end of life: exploring theoretical and cultural congruence with dignity therapy. J Adv Nurs. 2014; 70: 2920-31, DOI: 10.1111/jan.12455.

Supporting Information

S1 Table. Methodological Quality of included studies assessed with CASP: qualitative research checklist

S2 Table. Quotations from participants in the primary studies that illustrate each theme

S3 Table. Methodological Quality of the systematic review assessed with AMSTAR (a measurement tool to assess systematic reviews)

S1 Table. Methodological quality of included studies assessed with CASP Critical Appraisal Skills Programme: qualitative research checklist.

CASP: Critical Appraisal Skills Programme [27]	Bolmsjö [40]	Mesler and Miller [33]	Lavery et al. [38]	Chochinov [30]	nes [16]	Ganzini et al. [34]	Coyle and Sculco [35]	Volker et al. [36]	Volker et al. [37]	Mak and Elwyin [44]	Pearlman et al. [24]	Chapple et al. [42]	Franklin et al. [41]	Pleschberger [17]	Nissim et al. [39]	Brown et al. [43]	Ho et al. [45]	Ho et al. [46]
1) Was there a clear statement of the aims of the research? Consider:																		
– What the goal of the research was	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
– Why it is important?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
– Its relevance?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
2) Is a qualitative methodology appropriate? Consider:																		
– If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
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?)	--	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	--	✓	✓	✓	✓	--	✓
4) Was the recruitment strategy appropriate to the aims of the research? Consider:																		
– If the researcher has explained how the participants were selected	✓	✓	✓	✓	--	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	--	✓
– If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study	--	✓	✓	✓	--	✓	✓	--	--	✓	✓	✓	✓	✓	✓	✓	--	✓
– If there are any discussions around recruitment (e.g. why some people chose not to take part)	--	--		--	--	✓	✓	--	--	✓	--	--	✓	--	✓	--	--	✓
5) Were the data collected in a way that addressed the research issue?																		
– If the setting for data collection was justified	✓	✓	✓	✓	--	✓	✓	--	--	✓	--	--	✓	✓	✓	✓	--	✓
– If it is clear how data were collected (e.g. focus group, semi-structured interview, etc.)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
– If the researcher has justified the methods chosen	--	✓	--	--	✓	✓	--	✓	✓	✓	✓	--	✓	--	✓	✓	✓	✓
– 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?)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
– 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.)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
– If the researcher has discussed saturation of data.	--	--	✓	--	--	--	--	--	--	--	--	--	✓	✓	✓	✓	--	--
6) Has the relationship between researcher and participants been adequately considered? Consider whether it is clear:																		

CASP: Critical Appraisal Skills Programme [27]	Bolmsjö [40]	Mesler and Miller [33]	Lavery et al. [38]	Chochinov [30]	nes [16]	Ganzini et al. [34]	Coyle and Sculco [35]	Volker et al. [36]	Volker et al. [37]	Mak and Elwyn [44]	Pearlman et al. [24]	Chapple et al. [42]	Franklin et al. [41]	Pleschberger [17]	Nissim et al. [39]	Brown et al. [43]	Ho et al. [45]	Ho et al. [46]
If the researcher critically examined their own role, potential bias and influence during:																		
– Formulation of research questions	✓	✓	✓	--	--	✓	✓	--	--	--	✓	✓	✓	✓	--	--	✓	✓
– Data collection, including sample recruitment and choice of location	--	✓	✓	✓	--	✓	✓	✓	✓	✓	✓	✓	✓	✓	--	--	✓	✓
– 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	✓	✓	✓	✓	--	✓	✓	--	--	✓	--	✓	✓	✓	✓	✓	✓	✓
– 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	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
8) Was the data analysis sufficiently rigorous? Consider:																		
– If there is an in-depth description of the analysis process	--		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
– If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
– Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process	--	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	--	✓	✓	✓
– If sufficient data are presented to support the findings	--	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	--	✓	✓
– 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	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
– If there is adequate discussion of the evidence both for and against the researcher's arguments	--	--	✓	✓	--	--	✓	✓	✓	--	✓	✓	✓	--	✓	--	✓	✓
– If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.)	--	--	✓	✓	--	✓	✓	✓	✓	--	✓	✓	--	✓	✓	✓	--	✓

CASP: Critical Appraisal Skills Programme [27]	Bolmsjö [40]	Mesler and Miller [33]	Lavery et al. [38]	Chochinov [30]	nes [16]	Ganzini et al. [34]	Coyle and Sculco [35]	Volker et al. [36]	Volker et al. [37]	Mak and Elwyin [44]	Pearlman et al. [24]	Chapple et al. [42]	Franklin et al. [41]	Pleschberger [17]	Nissim et al. [39]	Brown et al. [43]	Ho et al. [45]	Ho et al. [46]
– If the findings are discussed in relation to the original research questions	--	--	✓	✓	--	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
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?)	--	✓	✓	✓	✓	✓	✓	✓	✓	--	✓	✓	✓	✓	✓	✓	✓	✓
– If they identify new areas where research is necessary	--	--	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
– 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	--	--	✓	✓	✓	✓	✓	✓	✓	✓	--	--	--	✓	✓	--	--	✓

S2 Table. Quotations from participants in the primary studies that illustrate each theme

Theme: Dignity mediated by the loss of functionality	**Other related themes**
Subtheme: Loss of control	
Interviewer: “Ok and what do you mean by dignity?” Participant: “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 [sic] 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.” [38]	Dependency Inability to perform daily living activities Loss of identity
“I am so angry when I have only one side that works, when I have been a hands-on person all my life. I get angry and frustrated because I can’t do things that used to be so easy for me to do.” [30]	Inability to perform daily living activities
“But I guess that [dignity] is something that I’ve lost... [Knowing] it’s going to get worse. I know it will [be] quick, or I hope so. When I get to the point where I can’t go to the bathroom anymore or where I can’t... all the things that I still have control over... I suppose maybe you get to the point where you have to be all plugged into a whole bunch of stuff and tubes and everything else. But maybe you go so far down the road those tubes... Maybe it doesn’t matter anymore. But I’m not looking forward to that day... You know, I just heard in the last couple of minutes you sort of... [I’m] worried and scared. But it’s just something that you thought about the timing and circumstance of... I guess I worry about it more than I think...Yeah. I don’t know what’s in store and I think my fate is, you know, the time and what it brings me sort of thing. It doesn’t make it easy.” [2]	Inability to perform daily living activities Fear of future suffering
“Well it’s the same thing as living in your own home you know. You are your own person. And… and if anybody started telling me to do this do that you know, and you’ve got to be in bed at a certain time and you’ve got to have help being undressed and all that, I think… God Lord, that... would be the worst thing that could happen. That would really be losing dignity. I wouldn’t have any then.” [2]	Loss of independence
“She was totally bedridden. She was messing her sheets and stuff like this, and Mother just—I mean, she’s just—she was a very fastidious person. And she just—she—well, basically, she thought the quality of her life was appalling. She couldn’t do anything. All she could do was lie in bed.” [24]	Loss of quality of life
“To the most—the simplest things, and when they were gone, he didn’t have a reason... So it wasn’t just the diarrhoea or the lack of driving; it was just losing, like, his definition—what his sense of vitality was. And when that was gone, then he was ready.” [24]	Loss of identity Loss of control
“The nurse was over there, basically, manually helping her along… And she just said, ‘This is not worth it’… And a lot [had] to do with her as a person where she just was so independent. The whole idea of nursing to her was just abhorrent.” [24]	Loss of independence Social identity: perceived vulnerability
“I am afraid of the day when I can’t even get out of bed.” [41]	
"No one told me that I had cancer in the beginning, not my doctor or my children", said an 82-year-old home-dwelling female patient. ‘They didn’t want me to be upset, I guess, but I have a right to know. I finally got the answer from a second doctor that I consulted, and honestly, I wasn’t upset to hear the news. I mean I have lived a long life and all my children have grown up. I am not afraid of dying... but I don’t want any more painful medical procedures. After talking to my attending nurse, I signed off my advanced care directives so that my family members don’t have to make those difficult decisions for me.’” [46]	Loss of control over information Decision making

Subtheme: Value of one’s own life	
“I recognized only later that my patient’s goal was to be released from a life that had robbed her of her independence and dignity.” [29]	Loss of control over one’s circumstances
“My patient was suffering at the core of her being without agonizing pain, anorexia, or night sweats. She had become increasingly dependent on others for virtually all activities. Her dignity, her self-esteem had been stripped away. The vitality of her being had passed. Yes, her life, as she defined it, had become futile.” [29]	Dependency Loss of self-esteem Inability to perform daily living activities Loss of the value of life
“You talk about dignity... I’ve decided what I aim to do [I always wear make-up anyway, which I can’t do now], I’m going to make sure that I always have my make-up on; make sure everything is very clean, very tidy and my nails properly done...” [16]	Inner dignity Physical image
“He told me that if all you can look forward to is your next enema, and you don't even like that much, what is the point of living?” [34]	Loss of the value of life
“It would be a comfort to me to think that when I’ve come to a point where I’m clearly dying, you know there is no further treatment available for me and if I am in lots of discomfort, I would like to be able to say, ‘Can you get my kids to come and see me,’ and maybe, I don’t know, my friend, that’s a minister or whatever and say goodbye. And then [er] you know can you just do what has to be done, give me an overdose of morphine or whatever it is. Because actually my Mum was in hospital for about three months before she died. And she had sort of raging osteoporosis having taken lots of steroids for another condition. And she was in terrible pain and she had made a living will actually. [Um] And they had to give her so much morphine in the last few weeks, to be honest she was talking rubbish and coming up with ideas. She told us there was something she wanted to tell me and that she had murdered twelve children. And I said, ‘Oh Mum, you know that is your mind playing tricks because of the drugs. You haven’t murdered anybody’. But she still insisted that she had. And I just wish that she could have gone a month or two earlier before she went through all that indignity that is dying really. [um] And I would feel the same about myself [...]. I just think that when you’ve come to that stage, only you know when that is, how bad that has to be, you don’t need to go through the physical indignities of throwing up, being smelly, being incontinent, whatever it might be.” [42]	Loss of functionality Fear of future suffering Desire to hasten death
“I can’t do anything. Since they amputated my legs I just wheel around in my wheelchair.” [41]	Inability to perform daily living activities
“I just lie here; you see I can’t move, my body just won’t let me. I used to be very active and travel a lot.” [41]	Loss of functionality
“If you lose your mind you will soon lose in value.” [17]	Loss of the value of life Loss of functionality
“Dignity is really about living a normal life... being able to eat what I like, do things that I enjoy, and be with my family give me dignity.” [45]	Performing daily living activities Independence
Theme: Dignity as identity	
Subtheme: Self-Identity	
“You’ve become a bag of potatoes to be moved from 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.” [38]	Loss of self-esteem Feeling of being useless Loss of the value of life
“I think to be calm is dignity. I’ve never been a calm person and I hate myself sometimes for that… I’m becoming more calm. I’ve control... To be in control of your emotions; that’s dignity.” [16]	Inner dignity
“She [patient] used to be a pretty dynamic lady. She has a brain tumour and it - she had everything because of her high steroids... She put on so much weight that her body image... changed... and she finds that the way she eats is so grotesque… way of eating. She knows that she’s wrong and she’s like: ‘I lost - I lost my body image and I don’t care.’” [16]	Physical image

“Said [to the patient], ‘Well, what do you want to do?’ And she said, ‘Well, what am I allowed to do?’ And I said, ‘What you want to do’. She said, ‘You mean I can decide what I want to do?’ I said, ‘Yeah, what do you want to do?’ She said, ‘I want to take all these tubes out and I want to go home and to go back to church and do clog dancing.’ I said, ‘Well, what if… not your spirit, not your soul… but your physical body isn’t going to do that? What else is important?’” [36]	Inner dignity
“Everybody needs their space. Even though you need to be compassionate, still respect their space. When I’m really in pain, just totally a mess, let me have my space. I don’t know about other people, but that’s one thing about me. When I’m really, really bad, I just want to be left alone.” [37]	Need for independence Importance of privacy
"I've seen patients yelling in pain and they were suffering… so intolerable… Just to hear them was very suffering… It must have been so unbearable to have to yell like that. If they could endure it, they wouldn't have yelled." [...] Someone with a tube ticking up the bottom, a tube sticking into the nostrils, another somewhere else- I mean, what for? Can you save them?" [44]	Loss of the value of life Suffering
“When I lost my hearing people started to ignore me. They didn’t treat me as a human being anymore and then when I lost my eyesight there was nothing left. I couldn’t go anywhere and couldn’t do anything. For example, I can’t hold the telephone and it’s impossible for me to put it back if no one helps me. My friends want me to contact them as well but I can’t without asking the girls and they have so much to do and are in such a rush so I forget to ask when they are in here.” [41]	Loss of social recognition Inability to perform daily living activities
“I am highly pleased anyway, as long as you can help yourself it is wonderful in this place. But when you cannot help yourself and get ill then it is not that jolly any longer.” [17]	Loss of the value of life
“I stopped worrying about this and that as I really have little control over things... all I am concern about is living in the moment and spending time with my family.” [45]	Inner dignity Living the present
Subtheme: Social factors	
“I wish I didn't have to vomit, pass waste, and so on uncontrollably. Looking disgusting is never dignified. Being sad, angry, scared, and so on hasn't got anything to do with dignity if you the staff, I think you can keep your dignity even if you do look distinguishing. I'm just now wondering whether perhaps losing one's dignity is like getting into situations where you would normally feel embarrassed and ashamed. There probably aren't too many situations where you can lose your dignity in the eyes of those closest to you. Getting to know one another is important.” [40]	Loss of functionality Inner dignity Social identity
“I'm scared of ending up like a vegetable. I can't even think about that - being so dependent that I can't manage anything… helplessness and pain. There's some hope in being able to go through a difficult crisis and pull back again. Think what it must be like to need help going to the toilet, help washing yourself, perhaps not being able to talk, express oneself. Suicidal ideation: I'm afraid of ending up just lying there, not being able to do anything, and just waiting to die. In that case, I'd rather take an overdose.” [40]	Loss of functionality Fear of dependency Desire to hasten death
“Well I think you lose your dignity when you’ve got to be fed. I mean you feel so foolish. You know I really did not want to be fed. But they kind of... they forced me. Having to be waited on and looked after and maybe even fed. I don’t know. But I… oh I would hate that. I like to be independent.” [2]	Dependency Loss of identity
“Actually for us it's been fairly few patients that ring so clearly in my mind, where they were just in pain until the end. But even the people that aren't in pain have to go through so many indignities - you have people bathing you, and touching you, and there's no privacy. I wouldn't want to go through it; no way.” [33]	Loss of functionality Dependency
“And I was on the commode and I had to be wiped and I just about cried my eyes out because of... you know, I never felt... I said to the nurses, God, who would have ever thought it would ever come down to this. I got these diapers or whatever it is that they call it... And that’s presenting a problem. I don’t like to think of myself as that. Things like that. That’s my dignity and it comes down to types of things like that really...So I get mad.” [2]	Loss of functionality Dependency Suffering in relation to one’s vulnerability

Interviewer: “Are there other things that would take dignity away from you?” Participant: “Having that young woman come in here the other day was very, very hard on me. Or to ask her to do anything for me, I find it very hard to ask her anything. I don’t know how to describe it. For one thing, I’ve never had too much self-esteem I suppose and I always preferred to meld into a wall. I felt more comfortable there… Uh, things like not being able to go to the washroom by myself. Oh to me, that would take everything away from me because I am so modest.” [2]	Loss of functionality Dependency
Interviewer: “What would take dignity away from your life?” Participant: “Oh my God, maybe putting me on the toilet seat. These are private things, you know. I still feel like I like my privacy. Even for my sleeping in, it’s kind of embarrassing if I’m still sleeping if they come downstairs. You know I’ve got to be... I’ve got to be up first and get dressed and be here...” [2]	Dependency Importance of privacy
Interviewer: “Would you feel that your dignity was taken away if your children needed to help you?” Participant: “Well, yes if I knew... I wouldn’t want them to take on the burden of doing that. That I have to depend on people just to look after me, to wash me, to take me to the bathroom and to cleanse… clean me up... I know this happens but I wish it didn’t happen to me.” [2]	Dependency Fear of being a burden on others
“It’s going to the loo... in privacy... with locks on the doors... and not leaving a mess in the loo... for other people to clean up. Em, trying not to make nasty smells... I know this sounds silly ’cos... Its dignity…” [16]	Independence Importance of privacy
“Telling someone that... that maybe their vision is impaired and they may not be able to read again is a devastating blow for someone but it doesn’t have any knock on implications from the point of view, necessarily of their dignity. But telling someone that they won’t be able to em, toilet themselves, that seems really sort of - very devastating for someone...” [16]	Loss of functionality Dependency
“Professional W: `Anything that affects their, I suppose *capacity* to self-care and to be ever increasingly dependent on others would have an impact on the fact there’s a dignified human being.’” [16]	Loss of functionality Dependency
“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.” [35]	Suffering in relation to one’s vulnerability
“When I’m in the hospital, I don’t like to have tubes in me and I don’t like people coming in and seeing those things in me. I want them hidden because it’s very uncomfortable for everyone. The last time I was in the hospital, I had a visitor with me. And it wasn’t a family member. The nurse came in to check my [urinary] catheter to see how much it drained and to empty it. It just caught me so off guard. I didn’t appreciate that, because it’s like sharing my urine with other people.” [36]	Importance of privacy Social identity
“As far as dignity’s concerned, it’s just like last night [after falling and requiring paramedic intervention]. My dignity was hurt more than the bruises I’ve got. My pride and everything was gone at that point. It’s been hard having to stay with my son. That’s a great break in the independent thing. When I moved down here, my son said, ‘I never ever expected to have a wheelchair in my front room. I just can’t accept the fact that I cannot work anymore and have to live with him because I can’t afford to live on my own because I can’t afford the help.’” [36]	Dependency
“I said, ‘No, you can’t give Neulasta on the same day as Gemzar® [gemcitabine hydrochloride, Lilly Oncology, Indianapolis, IN]; I’m going to have to come back tomorrow.’ And so the next morning, I called another nurse, and she said, ‘No, absolutely not; we don’t give Neulasta with Gemzar.’ This can be quite scary. Because you take a healthy patient like me and kill ’em. It really makes me mad. I’m really considered what I think is a pretty difficult patient because I’m so on top of what has to be done to me.” [36]	Decision making
“I can’t move, just lie here... feeling like a vegetable... a useless person… needing people to feed me.” “I just don’t want to endure these psychological effects… So much suffering... I have had the pain for four years… So many psychological effects… How can I bear it?” “Wish to live but can’t live; wish to die but can’t die.” [44]	Dependency Loss of the value of life Suffering in relation to one’s vulnerability Identity

"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." [24]	Dependency Loss of the self
"He said that he doesn't want to just turn into this vegetable kind of person where you're not aware of what's going on, and that everybody around you is affected; everybody's having to take care of you, feed you, clean you, give your medication." [24]	Dependency Loss of the self
"One patient reported, ...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." [24]	Suffering in relation to one's vulnerability Social identity
"I need help with everything; I can't even go to the bathroom by myself." [41]	Inability to perform daily living activities
"It's horrible not being able to take care of myself. I can always get help but it's horrible to wake up when you wet your own bed. Everything you do you're dependent on others. For example, when you need to go to the toilet. It doesn't feel good to ask for help going to the toilet, just like babies." [41]	Inability to perform daily living activities Suffering in relation to one's vulnerability
"I'm scared of being dependent, tied to the bed and not being able to take care of myself, but there is no point in worrying. I try to enjoy the moment. The sun is shining or a flower is blooming… things like that." [41]	Suffering in relation to one's vulnerability Social identity
"[…] And that is a horror for me, that I might possibly have to lie in bed from morning to evening and from evening to morning and that I am dependent on another person to make every handhold that is important for my care and support. That I cannot any longer do everything alone, that is a terror for me. And I say, quite honestly… when I pray, I pray that I may also be spared that." [41]	Dependency
"You know they just demand to take over all the time...they could ask." [39]	Decision making
"I am totally dependent on my wife to carry me down the stairs, out of my home and into the outside world... My friends just seemed to have disappeared in my life." [45]	Loss of social recognition Dependency
"When I first got sick and was admitted to the hospital, I came out of surgery feeling very weak...I couldn't eat under my own strength and the nurses came by a few times offering to feed me. I have never been fed since childhood, but if life has come down to this, I would want my daughter to do it." [45]	Dependency
"When I got out of the hospital my daughter became very conscious and restrictive of my diet. She didn't allow me to eat fatty food or go out for tea at my favourite restaurant... I got so angry at one point that I said, ''I am going to die soon, so just let me eat what I want, and let me die a happy and fulfilled woman." [45]	Loss of independence
"I don't want to be a burden to my family and I want to have a say in the kind of care that I receive… But life here is harsh. I have no say in what to eat or when to eat, and my life revolves around the working routine of staff members. I have to wake up and eat breakfast at five o'clock every morning because this is when the morning shift starts working." [45]	Fear of being a burden on others Loss of independence
Theme: Autonomy as a determining factor of perceived dignity	
Subtheme: Desire for control over the dying process	
"It was extraordinary important to Diane to maintain control of herself and her own dignity during the time remaining to her […] Knowing of her desire of independence and her decision to stay in control, I though this request made perfect sense." [28]	Desire for control over the dying process Desire for independence
"She was convinced she would die during the period of treatment and would suffer unspeakably process" [from hospitalization, from lack of control over her body, from the side effect of the chemotherapy and from pain and anguish]. [28]	Fear of suffering Loss of control over functionality Loss of quality of life
"She was frightened to be leaving, but that she would be even more terrified to stay and suffer." [28]	Fear of future suffering [more than of death itself]

“It was also evident that the security of having enough barbiturates available to commit suicide when and if the time came would leave her secure enough to live fully and concentrate on the present.” [28]	Security of being in control
Participant: “If I’m going to be rolling around in my own faeces because I have no control, then forget it.” Interviewer: “Ok. Why—why is that such an important thing?” Participant: “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... Dignity is that I have control over my body, when, when, not, 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.” [38]	Loss of identity Desire for self-determination
“Reasons for requesting assisted suicide more often had to do with future fears of suffering rather than current suffering: ‘He was very fearful of what the end might be like. He was worried about the pain. He was worried about the shortness of breath. And yes, he was very up-front about being afraid to die in misery.’” [34]	Fear of suffering
“His family said what he really wants is control, he doesn’t want to lose control.” [34]	Desire for control
“The option to extract oneself from an untenable situation through a hastened death sometimes was expressed as an “if-then” proposition; for example, ‘If the pain gets worse, then I want to be dead.’ ‘Pain is my biggest fear. It puts me in darkness and a lack of will to go forward and a desire to die… The pain wants me to have a vehicle to just, just stop my life.’” [35]	Fear of suffering
“There’s a fear about having pain and losing dignity when they die. Patients say, ‘When I die, I hear that I may wet myself, or mess myself.’ And that’s a big issue.’ Another APN observed that her patient’s increasing weakness ‘was the thing that took a lot of her control away’ and injured her pride in her ability to independently manage her complex physical care needs.” [36]	Fear of suffering and of the loss of control
“The patient said, ‘I don’t want strangers in my house. I’m doing fine. My wife’s taking care of me. I just don’t want people there 24 hours a day telling me what to do. And so I have had people refuse hospice because their understanding is that hospice takes control of their personal lives. They are very afraid of people coming in and they don’t want anybody to take over the role of their caretaker.’” [36]	Desire for independence Importance of privacy
“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.” [24]	Decision making
“One family member described her mother as an extraordinarily independent person, absolutely needing to be in control of her life all the time and already felt—how shall I put it—she had problems with feeling not in control.” [24]	Desire for independence
Participant: “I myself want to be in control as long as I can, I don’t want doctors and nurses controlling me [...] I’m on morphine, I get a lot of breakthrough pain, when I get to the pitch where I really can’t cope with anything any more, where my quality of life is totally gone, I will tell my husband I want a really good day out with the kids which is when he’ll know that when I go to bed that night I won’t wake up the next morning: [...] I think that you have to really look into it seriously, whether this is the right thing for the right person because I think there is the risk it might be abused. But with myself, if the legislation was there then it would be nicer for me, so I’m not on my own, which I know I will be because I don’t want any of the family here when it happens.” Interviewer: “Why don’t you want anyone with you?” Participant: “Because I don’t want them involved, I don’t want them to get in trouble. [...] In other countries, [...] I believe now, you’re allowed to choose when you die so you’ve still got your dignity. This country we don’t allow it; [...] if anybody helps us they lock them up, which is wrong. You’ve taken away that person’s dignity and nobody should have the right to do that. We should all have the right to choose when we die and how we die”. [42]	Loss of the value of life Desire for self-determination

“I never thought about giving up but my fear was that I didn’t know much about cancer. There are so many people that linger, and I was afraid that I could not cope. I know I will die, but I don’t want to be lingering and suffering and people around me to suffer with me. So I thought, ‘I will go for a swim’ and I don’t know how to swim or I would go to a place like Holland. I just don’t want to be lingering, like people that can hardly talk and are really suffering and I don’t want to do that. I t’s the only thing that makes me feel a little bit emotional. I don’t want to deal with it so I think I would speed up things myself. I don’t want to be lingering here in palliative care, lying day and day, slowly dying. Oh no, I don’t want to do that. So, suicide is a way of exiting. I don’t want to talk about that because I like life and I have lots to live for, but if I come to the point when I am too weak to do anything, then I don’t want to stay.” [39]	Fear of suffering and of making others suffer Desire to hasten death
Subtheme: Desire for self-determination	
“So she was a control person. You know, we are talking big time control... You know, I am in charge here. She sort of self-directed her medical care... It was a control issue, not a pain issue...’I want to be in control of my destiny. I don’t want to go out as, you know, incontinent, in pain, crying, you know tearful person. I want to go out with some dignity’”. [34]	Loss of functionality Loss of the value of life Desire for self-determination
“She just felt this was not dignified at all for a woman who had been in control all of her life. And she knew the end was near anyway. And she said, ‘I want to do it on my terms. I want to choose the place and time. I want my friends to be there. And I don’t want to linger and dwindle and rot in front of myself.’” [34]	Desire for control over the end-of-life process Desire for self-determination
“When I saw her she was very, very weak and very dehydrated. And again, I told her, I said, ‘Gee, you’re within a couple days probably of losing consciousness just from dehydration, and we could make sure that you just slept and did not suffer and it would just be a short time.’ She had the 15-day wait and she had 4 days before the medicine could be prescribed. And I told her that I didn’t think she would be able to do that unless she could solve the nausea and dehydration that she would last for 4 days consciously and to take the medicine. And she sort of struggled into a sitting position, asked her husband to get her a glass of water, and said, ‘I’ll get the fluids down somehow.’ And sort of forced… See, this is the paradox, this is where you learn that lesson about the control issue—she actually reversed the natural process to prolong her suffering, in order to be in control, to push the button herself.” [34]	Desire for control over the dying process Desire for self-determination
“I don’t want to undergo that (explicative) feeling of helplessness, that there’s not a (explicative) thing that I or anyone else can do, or “Sometimes I start yelling at my shrink that this is horrible, that why don’t I die right now? Why do I have to live through this? Related with: I don’t want to go through the dying process so I’ll kill myself.” [35]	Feeling of being useless Suffering Desire to hasten death Desire for self-determination
“I think that anybody with a terminal illness should have the right to assisted suicide. I think that should be a fundamental right people have. I wouldn’t like to be like that sick poor man who was in the news recently who put a plastic bag on his head. I mean, he must have felt really bad to be able to do that, and I’m sorry that he had to do that because he should have had a more dignified option, and he shouldn’t have had to do it by himself.” [39]	Desire for self-determination Right to choose

S3- Methodological Quality of the systematic review assessed with AMSTAR (a measurement tool to assess systematic reviews)

1. Was an 'a priori' design provided? The research question and inclusion criteria should be established before the conduct of the review.	[✓ ☐ Yes] ☐ No ☐ Can't answer ☐ Not applicable
2. Was there duplicate study selection and data extraction? There should be at least two independent data extractors and a consensus procedure for disagreements should be in place.	[✓ ☐ Yes] ☐ No ☐ Can't answer ☐ Not applicable
3. Was a comprehensive literature search performed? At least two electronic sources should be searched. The report must include years and databases used (e.g. Central, EMBASE, and MEDLINE). Key words and/or MESH terms must be stated and where feasible the search strategy should be provided. All searches should be supplemented by consulting current contents, reviews, textbooks, specialized registers, or experts in the particular field of study, and by reviewing the references in the studies found.	[✓ ☐ Yes] ☐ No ☐ Can't answer ☐ Not applicable
4. Was the status of publication (i.e. grey literature) used as an inclusion criterion? The authors should state that they searched for reports regardless of their publication type. The authors should state whether or not they excluded any reports (from the systematic review), based on their publication status, language etc.	☐ Yes [✓ ☐ No] ☐ Can't answer ☐ Not applicable
5. Was a list of studies (included and excluded) provided? A list of included and excluded studies should be provided.	[✓ ☐ Yes] ☐ No ☐ Can't answer ☐ Not applicable
6. Were the characteristics of the included studies provided? In an aggregated form such as a table, data from the original studies should be provided on the participants, interventions and outcomes. The ranges of characteristics in all the studies analyzed e.g. age, race, sex, relevant socioeconomic data, disease status, duration, severity, or other diseases should be reported.	[✓ ☐ Yes] ☐ No ☐ Can't answer ☐ Not applicable

7. Was the scientific quality of the included studies assessed and documented? ‘A priori’ methods of assessment should be provided (e.g., for effectiveness studies if the author(s) chose to include only randomized, double-blind, placebo controlled studies, or allocation concealment as inclusion criteria); for other types of studies alternative items will be relevant.	[✓ ☐ Yes] ☐ No ☐ Can’t answer ☐ Not applicable
8. Was the scientific quality of the included studies used appropriately in formulating conclusions? The results of the methodological rigor and scientific quality should be considered in the analysis and the conclusions of the review, and explicitly stated in formulating recommendations.	☐ Yes ☐ No ☐ Can’t answer [✓ ☐ Not applicable]
9. Were the methods used to combine the findings of studies appropriate? For the pooled results, a test should be done to ensure the studies were combinable, to assess their homogeneity (i.e. Chi-squared test for homogeneity, I^2). If heterogeneity exists a random effects model should be used and/or the clinical appropriateness of combining should be taken into consideration (i.e. is it sensible to combine?).	☐ Yes ☐ No ☐ Can’t answer [✓ ☐ Not applicable]
10. Was the likelihood of publication bias assessed? An assessment of publication bias should include a combination of graphical aids (e.g., funnel plot, other available tests) and/or statistical tests (e.g., Egger regression test).	☐ Yes ☐ No ☐ Can’t answer [✓ ☐ Not applicable]
11. Was the conflict of interest stated? Potential sources of support should be clearly acknowledged in both the systematic review and the included studies.	[✓ ☐ Yes] ☐ No ☐ Can’t answer ☐ Not applicable

Segundo artículo: A philosophical view on the experiences of dignity and autonomy through the phenomenology of illness

Presentación del segundo artículo de esta tesis:

En el seno de la Cátedra WeCare, donde se investiga sobre atención al final de la vida desde un punto de vista clínico, empírico y aplicado, la mirada de alguien que procede de las Humanidades, muchas veces es, podríamos decir, de ‘alquimista conceptual’. Si, según la Real Academia Española por *alquimia* se entiende “transmutación maravillosa e increíble” (2014b), podríamos decir que, volviendo a la imagen de la mirada, la perspectiva filosófica permite tomar la experiencia ordinaria de las personas (lo que los profesionales de la salud, pacientes y familiares viven –y padecen– de forma cotidiana) y transmutarla en, como dice Toombs, “un proyecto reflexivo, que parte de nuestra experiencia del mundo y se convierte en nuestro foco de reflexión” (1992, p. xi). En este sentido, es claro cómo el testimonio de los participantes de los estudios cualitativos se presta como “voz de la experiencia del mundo” y, el marco filosófico-antropológico establece las bases para que pueda desarrollarse la reflexión, tematizando el significado de esta experiencia.

Siendo conscientes también de la limitación que supone ceñirse al tamaño reducido de verbatims para la publicación de un estudio secundario, en este análisis, partiendo del nivel más descriptivo, se pretende llegar a un nivel más alto de abstracción bajo el marco teórico de la fenomenología de la corporalidad de K. Toombs. A la vez que limitación, la aproximación directa a la realidad vivida de los pacientes que viven en estas circunstancias es también una fortaleza. Este estudio no pretende seguir aportando categorías a la fenomenología de la corporalidad sino profundizar en la experiencia vivida para entender y comprehender esta vivencia desde una mirada integradora, que incluso, sirva de reflexión e influya en el cuidado que se da a los pacientes.

A PHILOSOPHICAL VIEW ON THE EXPERIENCE OF DIGNITY AND AUTONOMY THROUGH THE PHENOMENOLOGY OF ILLNESS

Running head: A philosophical view on dignity and autonomy

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ABSTRACT

In the context of the end of life, many authors point out how the experience of identity is crucial for the wellbeing of patients with advanced disease. They define this identity in terms of autonomy, control or dependence, associating these concepts with the sense of personal dignity. From the perspective of the phenomenology of embodiment, Kay Toombs and other authors have investigated the ways disease can impact on the subjective world of patients and have stressed that a consideration of this personal world can promote understanding and recognition of their experience.

Based on the findings of qualitative studies of the perception of dignity and autonomy in patients at the end of life, this analysis assesses concepts such as *being-in-the-world in illness*, *embodiment*, *lived body* vs. *objective body* or the *gaze of the other* from a Toombsian phenomenological perspective.

Key words: *phenomenology, dignity, autonomy, end of life, qualitative studies.*

I. THE MEANINGS OF DIGNITY AND AUTONOMY IN THE BIOMEDICAL CONTEXT

In recent years, there has been a growing interest in the situation of people who are at the end of life. Numerous studies have explored the experiences and attitudes towards identity, pain, or coping with the prospect of death of patients with cancer or other chronic or degenerative diseases (Emanuel and Emanuel 1998; Proulx 2004; Chochinov et al. 2002; Vig and Pearlman 2004; McNamara 2004). In this connection, the concept of dignity has emerged as a key factor deserving special protection in this time of real vulnerability (Chochinov et al. 2002; Chochinov 2002; Jacelon 2003; Enes 2003; Chochinov 2004; Chochinov 2007; Jacobson 2009). Indeed, the safeguarding of dignity has been identified as one of the goals of clinical practice, an indispensable attribute of the individual which must be preserved (Johnson 1998; Chochinov et al. 2002; Sulmasy 2005; Antiel et al. 2012; Vladeck and Westphal 2012).

Many studies and reports have attempted to define dignity and the factors related to it, how it is perceived by patients, by relatives and even by professionals (Chochinov et al. 2002; Walsh and Kowanko 2002; Enes 2003) and also to identify possible interventions for evaluating it and for improving its perception among people at this stage of life (Chochinov et al. 2008; Periyakoil, Kraemer, and Noda 2009; Vlug et al. 2011; Östlund, Brown, and Johnston 2012; Guo and Jacelon 2014). A key element is the perception of dignity mediated by the loss of autonomy or control, which has often been interpreted as a loss of one's own identity (Quill 1991, Lavery et al. 2001; Ganzini et al. 2003; Pearlman et al. 2005).

In *Towards further clarification of the concept 'dignity'* (1996), Haddock suggested an interesting approach to understanding dignity in the light of the interaction between what the concept means in itself and the thoughts and values associated with its perception. Taking this approach as our starting-point, we will try to distinguish between the meanings of dignity and autonomy which are often mentioned in the literature: dignity in the ontological sense (that is, referring to the human being, as a quality or intrinsic property), dignity as an empirical quality (that is, how it is perceived by the subject and others), and autonomy understood as control and self-determination. This conceptual grounding will serve as a basis for understanding the results of our earlier meta-ethnography (Rodríguez-Prat et al. 2016) and our phenomenological discourse (inspired especially by the work of Toombs), which we present and discuss below.

DIGNITY

Intrinsic dignity

Many of the studies that explore dignity refer to a first intrinsic, metaphysical or ontological level. Some authors have called this *basic* dignity, the inherent and inalienable value which every person possesses and which cannot be affected or eroded by the circumstances (Pullman 1996; Johnson 1998; Sulmasy 2013). This is the sense of dignity alluded to in talk of human rights: “the recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world” (UN 1948). In his logical-conceptual analysis, Sulmasy (2013) stressed that dignity is an intrinsic value that a person possesses in virtue of his/her condition as a human being.

Personal dignity

At a second level is *personal* dignity (or *dynamic* dignity), which is related to the perception of the individual and of his/her immediate environment (Leung 2007). As Street and Kissane (2001) stress, dignity is perceived by a person within a given context, and thus it is an embodied and dynamic "construct". What defines dignity is therefore unique to each patient (Chochinov 2004): it is measured in terms of a subjective construction conditioned by social, psychological and physical factors. For example, in the following quote from the study by Franklin, Ternestedt, and Nordenfelt (2006) on views of dignity among elderly people, one can clearly see how the perception of dignity can depend on various dynamic factors such as the social context, the loss of physical function or the inability to perform ordinary everyday activities:

“When I lost my hearing people started to ignore me. They didn’t treat me as a human being anymore and then when I lost my eyesight there was nothing left. I couldn’t go anywhere and couldn’t do anything. For example, I can’t hold the telephone and it’s impossible for me to put it back if no one helps me. My friends want me to contact them as well but I can’t without asking the girls and they have so much to do and are in such a rush so I forget to ask when they are in here.”

Or, for example: “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... Dignity is that I have control over my body” (Lavery et al. 2001).

AUTONOMY

Another crucial element at the end of life is the perception of dignity mediated by the experience of autonomy or control. When the sense of dignity is considered in these terms, it falls within the framework of *personal dignity*, as defined in the previous section.

Autonomy is often defined as "the human capacity for self-determination and independence", associated with the ability to make free, rational choices (Mesler and

Miller 2000). However, it also encompasses physical functionality (Chochinov et al. 2002; Enes 2003; Street and Kissane 2001, Guo and Jacelon 2014), the ability to maintain activities of daily living (Chochinov et al. 2002. Volker, Kahn, and Penticuff 2004a; Schroepfer, Noh, and Kavanaugh 2009), independence from others (Östlund, Brown, and Johnston 2012; Chochinov et al. 2007), and the ability to receive and act on appropriate information in accordance with one's own values and capacities (Lavoie, Blondeau, and Picard-Morin 2011). Thus, although in clinical practice the discussion of autonomy focuses on the experience of disease – for example, on the loss of physical function or control over the activities of daily life – it is also associated with personal identity and the patient's system of values and beliefs. In fact, reports like the one published annually in Oregon (a state where assisted suicide is decriminalized and which has established itself as a reference point in debates on the issue) and studies conducted in the Netherlands (Hall 1996; Veldink et al. 2002. Onwuteaka-Philipsen et al. 2003; Klinkenberg et al. 2004), the first European country to decriminalize euthanasia, in 2002, show that many of the people requesting to die do so because of the loss of autonomy or control over their lives and a loss of their perception of dignity.

In the biomedical field, autonomy is now seen as an indispensable model and value. The publication of the Belmont Report (National Institutes of Health 1979) and Beauchamp and Childress's Principles of Biomedical Ethics (1979) established the principialist model of bioethics in which autonomy is one of the fundamental components.

To date, studies focusing on the perception of dignity and autonomy have highlighted the understanding of patients' needs and concerns regarding their care. However, although "dignity" and "autonomy" tend to appear side by side in the literature, the link between the two concepts is ambiguous. Paradoxically, dignity frequently appears as a key argument in clinical, legal and philosophical debates, and is appropriated by opposing positions. A clear example of this ambiguous use of dignity is described by Pullman (1996), referring to a Canadian Supreme Court debate concerning a request for assisted suicide from a patient in a state of advanced amyotrophic lateral sclerosis. One of the five judges asked the question:

“As members of a society based upon respect for the intrinsic value of human life and on the inherent dignity of every human being, can we incorporate within the Constitution which embodies our most fundamental values a right to terminate one's own life in any circumstances?”

As Pullman notes, the speaker expected a negative response from his colleagues. However, two of the judges, also basing their argument on the question of dignity, replied:

“Security of the person […] has an element of personal autonomy, protecting the dignity and privacy of individuals with respect to decisions concerning their own body. It is part of the person and dignity of the human being that he or she have the autonomy to decide what is best for his or her body” (Pullman 1996).

In this case, the equivocal nature of the term “dignity” gave rise to the defense of diametrically opposed positions.

II. PERCEIVED DIGNITY, AUTONOMY AND CONTROL AT THE END OF LIFE: A SYSTEMATIC REVIEW AND META-ETHNOGRAPHY

Given this ambiguity of the relationship between dignity and autonomy, we proposed to carry out a systematic review and synthesis of previously published qualitative studies in order to explore this relationship from the point of view of the experience of patients at the end of life (Rodríguez-Prat et al. 2016). In this section we describe the methodology used to carry out the systematic review and meta-ethnography that has formed the basis for the present study.

In our search strategy, four criteria were used for the inclusion of articles: reference to patients (although the study samples could also include health professionals and family members); patients at the end of life (in processes of advanced disease or old age); reference to dignity or “death with dignity”, and finally reference to autonomy, also understood as control and self-determination. For the search we used the PubMed, Web of Science, Cochrane, CINAHL and PsycINFO databases.

After selecting the studies according to their titles, abstracts and full texts, and after removing duplications, the research team agreed on 21 studies for inclusion in the conceptual analysis.

For the analysis of the studies we used the meta-ethnographic method proposed by Noblit and Hare (1988). Through an inductive process, this procedure performs a systematic comparison of the findings in the primary studies with the aim of obtaining an interpretative synthesis rather than a mere description of the sum of the parts.

Three major themes emerged from the reading and rereading of the 21 studies. The first was the concept of dignity mediated by the loss of functionality. The second was dignity understood as identity. And finally, the third was autonomy as the foundation of dignity understood as the desire for control over the dying process and as the desire for self-determination (Rodríguez-Prat et al. 2016).

III. REFLECTIONS ON THE EXPERIENCE OF DIGNITY AND AUTONOMY THROUGH THE PHENOMENOLOGY OF KAY TOOMBS

Kay Toombs, who was diagnosed with multiple sclerosis in 1973, has combined her background as a philosopher with her personal experience of disease. She is the author of several scholarly works in the field of the phenomenology of the body, illness, and disability in chronically ill patients and is acknowledged today as one of the most important voices in these areas. Thanks to the philosophical and experiential value of her phenomenological discourse of illness we can establish a comparison between some of the concepts that she explores and the themes that emerged from the qualitative studies included in our analysis.

In the following section we outline some basic ideas of the phenomenology of the body and illness. Then, we apply a Toombsian perspective to the themes that emerged in the meta-ethnography.

THE PARADIGM OF THE LIVED BODY AND ILLNESS

The phenomenology of embodiment inspired or developed by major figures in the phenomenological movement such as Husserl, Merleau-Ponty and Sartre, has been applied retrospectively by certain modern-day authors to explore current issues and problems in the fields of health and of medical practice. A common underlying motivation of the work of Richard Zaner, Kay Toombs, Drew Leder, Fredrik Svenaeus and Havi Carel[i] is a concern with the dehumanization entailed by an understanding of the body or illness in purely mechanical, naturalistic or biological terms. In opposition to the Cartesian conception of the body as a machine, which is at the heart of modern medicine and the biomedical paradigm, the phenomenological perspective seeks to re-evaluate the experience of illness lived in the first person: that is to say, the experience of a lived body which is perceived as vulnerable, susceptible to pain, limited, fallible, and so on.

The starting point of this approach is, therefore, the distinction between the *objective body* of science and the *lived body* of experience. It is important to establish the difference between the two perspectives. The *objective body* is the body considered as a material reality, with physical properties (color, texture, shape) similar to other objects. This objective body can be studied and analyzed from outside, in the third person, with the view and perspective of the detached, neutral knowledge of natural science – as in the case, for example, of anatomy, physiology or neurology. In contrast, the *living* and *lived* body refers to the body as it is experienced by the subject itself, as the center of orientation around which the spatial dimensions of the world are organized: as the capacity for movement, action and relations with other beings, as an organ of the senses (capable of synchronizing with sensory qualities) and as a field of localization of sensations (cf. Husserl 1997 [1952], 143-161). While the objective body occupies a position in space alongside other objects, with a spatiality which is geometrically determinable, the living and lived body *inhabits* space and maintains a vital relationship with it. That is, it is always directed toward certain tasks or polarized by certain objects.

This distinction between the objective body of science and the lived body of experience should not, however, lead us to adopt a dualist position in which the two are diametrically opposed to one another, since in both everyday life and the experience of illness the body is always approached simultaneously from two perspectives, the objective and the subjective**.** Although it is true that there is always an *écart* (split) between these two facets that creates an existential tension, the *lived* and the *objective* body are not "two completely separate realities but, rather, different aspects of the same phenomenon" (Escribano 2013).[ii] For Sartre, this is illustrated in his analysis of the gaze, which we will return to later. For Merleau-Ponty,[iii] the interwoven reality of the lived and objectified body is exemplified in the image of two hands pressed together, with each being a touching-touched hand. Because of the experiential divergence between the subject-body and object-body the two hands alternate the role of 'touching' and of being 'touched'. By enriching the paradigm of the objective body with this new paradigm of the lived body, it may be possible to give a voice to the experience of the patient and thus rehumanize certain aspects of medical practice. At present, the excessive objectification or naturalization of the process of illness has unjustifiably minimized the importance of the personal dimension of disease itself, which has ultimately had a detrimental effect on the doctor-patient relationship.

The relationship with our own body, with the world around us and with others is profoundly impaired by motor disorders and incapacity, imprecision, and the fatigue they cause. People with these disorders face a series of new problems: difficulty in using everyday objects which they had previously used without any problem, a drastic reduction in their immediate spatiality or what was spontaneously achievable, a slowing down of their actions and experiences, the transformation of their self-image or the nature of the personal body, the loss of upright posture, the loss of control over basic physiological functions, the loss of sensation, and so on and so forth.

DIGNITY MEDIATED BY THE LOSS OF FUNCTIONALITY

The phenomenological paradigm unites body and mind and puts the body at the center of the surrounding world. Adopting this perspective endorses the fundamental conjoining of the terms body-self-world, which should not be dissociated from each other. However, their intertwining and articulation are greatly distorted by the onset of an illness.

This is why, although the living body is present in every action performed by a person in good health, it is “invisible”, “forgotten”, “silent” (Sartre 1993 [1943], 429-30). The healthy individual who wishes to move from one place to another experiences will, intentionality, directionality and execution through the body as one and the same, reflecting the extent to which the body is taken for granted as something inherently unproblematic. At a pre-reflective level, we are unaware of our control over our body when we set it in motion. In disease, however, we become acutely aware of our lived body. As the focal point through which we apprehend the world, as Toombs (1992, 54) states, illness cannot be seen as a simple organic alteration because the disruption of physical or functional capabilities goes beyond a mere mechanical dysfunction. So, if the body is intentional and is capable of responding to the outside world, disease weakens the person's communication with the world and represents a disruption of the intentional locus which renders this relationship highly problematic.

In the studies included in the systematic review, most participants report that disease entails a loss of physical function: it reduces the capacity to control the body (in the form of incontinence, loss of mobility, loss of cognitive functions, and so on) and limits the activities and circumstances of daily life (Bolmsjö 2000; Kade 2000, Lavery et al. 2001; Chochinov et al. 2002; Chochinov 2002; Ganzini et al. 2003; Coyle and Sculco 2004; Mak and Elwyn 2005; Chapple and Ziebland 2006; Ho et al. 2013a; Ho et al. 2013b).

For example, in Lavery et al.'s study of patients with HIV (2001) one of the participants defined his conception of dignity as: "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…"

Chochinov et al.'s study (2002) of advanced cancer patients and Franklin, Ternestedt, and Nordenfelt's study (2006) of the elderly report similar experiences:

"When I get to the point where I can't go to the bathroom anymore or where I can't... all the things that I still have control over... I suppose maybe you get to the point where you have to be all plugged into a whole bunch of stuff and tubes and everything else. But maybe you go so far down the road those tubes... Maybe it doesn't matter anymore."

And: “I just lie here; you see I can’t move, my body just won’t let me. I used to be very active and travel a lot.”

These testimonies of sick people also reflect the fact that they have to consider new ways of coping with everyday ordinary life. However, the loss of functionality, as well as the other factors that may affect the perception of dignity, should not in themselves be seen as something that impairs *human dignity*. This is because the value judgment comes later, and it is then, in their a posteriori attributions, that patients may come to feel that they have lost something of their dignity or, on the contrary, consider that despite their illness they can continue to live with a degree of normality or give meaning to their new situation. In the following quote from the study by Enes (2003), for example, one can see how patients may develop strategies for preserving a positive sense of dignity: “You talk about dignity... I’ve decided what I aim to do [I always wear make-up anyway, which I can’t do now], I’m going to make sure that I always have my make-up on; make sure everything is very clean, very tidy and my nails properly done...”

In a series of publications, Toombs herself has described her new relationship with the world as a multiple sclerosis patient. As a being-in-the-world, someone with a degenerative disease lives the coordinates of space and time with a heightened awareness: the effort required in having a shower or walking 100 meters may make us only too conscious of how we take the body for granted under normal circumstances.[iv]

DIGNITY AS IDENTITY

The second major theme that emerged from the studies was the idea of dignity understood from the perspective of identity: that is, how the subject perceives him/herself and how s/he constructs an image of him/herself through the eyes of others.

Identity (loss of the self)

In the “paradigm of the lived body”, illness is experienced not as a specific malfunction of the biological body, but more fundamentally as the disintegrating world of a particular person. For Toombs, the emergence of disorder and the experience of alienation bring with them a new way of being in the world.

The sick person no longer recognizes or identifies with his/her body and experiences it as an outsider. This is the concept of the “otherness of body” (Toombs 1988, 214). A sick person is paradoxically a subject who is not united with his or her body, and this lack of unity is experienced as an estrangement[v] between the body and the self. My body is objectified, and it undergoes a metamorphosis (cf. Toombs 1992). It becomes something that seems strange or foreign to myself, an “other-than-me” as Toombs calls it, something in which I cannot recognize myself, but which I cannot shrug off either.

Consequently, when I am ill, the perception of the loss of everything that made up my “self” is a common feeling (cf. Toombs 2001, 100). The paradox may even arise that my own body becomes a threat to me because the “self” cannot be separated from its embodied identity (Toombs 1992, 7).

Among the concepts examined by Toombs, the issue of body image emerged frequently in our review in relation to the concepts of the body as an object and of loss of identity. The studies by Bolmsjö (2000) and Pearlman et al. (2005) underline the fear of becoming a useless and dependent object which has lost its identity:

“I'm scared of ending up like a vegetable. I can't even think about that - being so dependent that I can't manage anything… helplessness and pain. There's some hope in being able to go through a difficult crisis and pull back again. Think what it must be like to need help going to the toilet, help washing yourself, perhaps not being able to talk, express oneself."

And: "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."

The notion of body image is intrinsically linked to the idea of the "lived body" in interaction with the world around it and with the possibility of projecting itself via "gestural display" (Toombs 1992, 56). It is through the body that a person perceives reality and generates and expresses meanings in a given context. In this way, one can say that the subject recognizes him/herself in his/her form of expression. Illness, by contrast, may imply a "change in the body's gestural display" (Toombs 1988, 208). For example, the inability to maintain an upright posture has been directly related to a loss of autonomy, dependency and feelings such as helplessness or fragility. The uncontrollable gestures that may result from an illness can also affect a person's gestural display, since the body then ceases to be a free expression of the self. Indeed, the ill body may communicate in ways the person experiences as inappropriate, and which may be misunderstood or shunned by others (Toombs 1988, 208-209).

In the experience of patients at the end of life, the body as an entity capable of transmitting a language is disrupted by the disease. Frequently, references are made to the lack of recognition of the self in this sick body. Several authors of qualitative studies who have explored the experience of embodiment in sick people have stressed this dissonance between the lived body and identity, and in the disharmony caused have noted that the body may be apprehended as an object.

In the Toombsian concept of "body as an object" the influence of Sartre's thought is especially striking.[vi] In the experience of disease, Toombs emphasizes that the gaze of the other has an alienating effect and makes the person an object: “To be looked at is to apprehend oneself as the unknown object of unknowable appraisals – in particular, of value judgments” (Sartre 1993 [1943], 267).[vii]

This gaze may originate in the sick person (i.e., the subject is able to look at him/herself).[viii] That is, my own act of looking at myself may objectify me, and, in so far as I see myself from the outside as a body, I can also see myself as an object. The quote below, referring to a patient admitted to a palliative care unit, draws attention to the process of physical deterioration due to advanced cancer:

“She (the patient) used to be a pretty dynamic lady. She has a brain tumour and it - she had everything because of her high steroids... She put on so much weight that her body-image... changed... and she finds that the way she eats is so grotesque… way of eating. She knows that she’s wrong and she’s like: ‘I lost - I lost my body image and I don’t care’” (Enes 2003).

Although the participant in this study does not actually make this point, often the change in body image is related to a loss of self-esteem (in fact, this quote does suggest a certain lack of interest on the part of the speaker in taking care of herself) and a certain disregard for the value of life.

Some patients also reported their concern at being remembered in their current state – as fragile and vulnerable, with their body ravaged by illness: “One patient reported, ‘...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’” (Pearlman et al. 2005).

Another interviewee expressed the idea of being treated as an object and how this might be linked to the loss of self-esteem and sense of dignity:

“You’ve become a bag of potatoes to be moved from 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” (Lavery et al. 2001)**.**

Social factors

This section on social factors will make more thematically central and explicit what was already present in the discussion of identity. Toombs (1992, 2) never considers the individual as an isolated entity; she always inscribes human nature in a historical, social and cultural framework which she calls *common world*: “Even one's unique biographical situation is *to some extent* a shared situation. That is, one's stock of knowledge… is for the most part culturally and socially derived.”

My way of being in the world (the way I smile, say hello, walk) allows communication with others. And these forms of representation “have the function of establishing a shared world of meaning” (1992, 8). In some cases, this shared world of meaning breaks down. On the one hand, the sick person somehow gives new meaning to his/her world, or the world takes on a new meaning for him/her; on the other, the new world created between the patient and his/her environment is mediated by the new situation of “illness” that forces him/her to take on new roles and new ways of seeing and understanding life.

For patients at the end of life, the meaning of social factors extends to all areas of how they perceive themselves and others (health professionals, family, friends and the immediate social environment) and to the ways in which social and professional roles change.

Among the most common experiences in these patients are the feeling of vulnerability and the worry of being a burden to others. We are back to the Sartrean idea of the gaze of the other. The gaze of the other makes me vulnerable and objectifies me; and, to the extent that it identifies me with my illness, it objectifies and alienates me.[ix]

The clinical gaze can become "objectifying" in so far as it is unable to comprehend this subjective, personal world, in need of a human and humanizing attitude that can help to mitigate this feeling of vulnerability. The following quote from Sartre might apply to many patients experiencing this tension of living in a body that is dependent on other people who may seem them as a burden:

"Pure shame is not a feeling of being this or that guilty object but in general of being an object; that is, of recognizing *myself* in this degraded, fixed, and dependent being which I am for the Other. Shame is the feeling of an *original* fall, not because of the fact that I may have committed this or that particular fault but simply that I have "fallen" into the world in the midst of things and that I need the mediation of the Other in order to be what I am. Modesty and in particular the fear of being surprised in a state of nakedness are only a symbolic specification of original shame" (Sartre 1993 [1943], 289).

Some terminally ill people object to being treated as patients rather than as human beings and stress the importance of this aspect of the treatment they receive from health professionals. The emotional vulnerability that characterizes disease lies in the fact that, very often, the identity of the "sick" person is configured from this being-for-others (cf. Toombs 1992, 35). And the fear that others will recognize the limitations imposed by the illness or weakness itself is easily translated to the fear and guilt of "being caught in a state of nakedness."

In qualitative studies of end of life, this gaze may have different meanings. On the one hand, the medical gaze, if it fails to take into account the experiential and embodied world of the patients, may have an alienating effect if its perspective is purely “objective”. From a Cartesian dualistic approach, the sick body can be converted into an object of scientific interest, into a “set of dysfunctional organs”. The following quote from the study by Volker, Kahn, and Penticuff (2004a) illustrates the dehumanization that may arise:

“When I’m in the hospital, I don’t like to have tubes in me and I don’t like people coming in and seeing those things in me. I want them hidden because it’s very uncomfortable for everyone. The last time I was in the hospital, I had a visitor with me. And it wasn’t a family member. The nurse came in to check my [urinary] catheter to see how much it drained and to empty it. It just caught me so off guard. I didn’t appreciate that, because it’s like sharing my urine with other people.”

On the other hand, the gaze, or the attitude, of the family and the immediate social environment are also crucial for personal recognition. Although the encounter with others can be alienating, it may also help a person maintain a positive sense of dignity, as can be seen in the following statement, made by a woman in a palliative care unit:

“Our dignity [hers and that of her husband] has been maintained because of the care we have been receiving in the hospital. The staff has been marvelous. They have been helping us as much as they can. I think part of dignity is trying to make him [her husband] feel that he is still of value” (Chochinov 2002).

AUTONOMY AS A DETERMINING FACTOR IN PERCEIVED DIGNITY

One of the essential characteristics of the lived body is that its experience of itself is limited; it does not possess or master itself completely. This means that I am exposed to phenomena of which I have no knowledge and over which I cannot exert full control. In this situation, it is the illness that best embodies the figure of the "other" that "possesses" me and acts in spite of me. Toombs (1992, 7) uses the metaphor of illness as a hidden and alien presence which is essentially beyond one's control.

Although this kind of "blind spot" with regard to the body has always characterized humankind, the experience of loss of control over life, circumstances and dying process is perhaps more acute for modern humans (cf. Toombs 1992, 94). The development and success of technology and science has led to an idea of disease as an unwarranted intrusion that must be eradicated by medical intervention. Patients consult health professionals with the unrealistic expectation that they can be completely cured. And to the extent that their expectations are not satisfied, their frustrations and anxieties increase, along with their fear of being unable to control the new situation. A direct consequence of this loss of control is that we now need for others to perform basic activities: "Illness, in its various forms, always impedes the ability to be self-reliant, to act on one's own behalf" (Toombs 1992, 94).

Patients at the end of life often refer to a perceived loss of dignity mediated by a loss of control over their life and their circumstances (Quill 1991; Bolmsjö 2000; Kade 2000; Mesler and Miller 2000; Lavery et al. 2001; Chochinov et al. 2002; Chochinov 2002; Enes 2003; Coyle and Sculco 2004; Volker, Kahn, and Penticuff 2004b; Pearlman et al. 2005; Chapple and Ziebland 2006; Pleschberger 2007; Östlund, Brown, and Johnston 2012; Ho et al. 2013a; Ho et al. 2013b). In these cases, some patients expressed feelings of helplessness and fear of future suffering, as well as a real frustration at being disabled and dependent on others.

Patients who expressed a strong desire for self-determination – for example, choosing practices that hastened their deaths – were often described as taking a particularly active part in their clinical process and as being especially sensitive to this loss of personal autonomy. In some cases, seeking one’s own death was seen as the last attempt to exert control over life and in a way over death as well.

In his famous case study of “death with dignity”, Timothy Quill (1991) described the situation of his patient Diane. The report proposes that assisted suicide is a justifiable way to end one’s life, especially in a patient with a strong, independent character:

“It was extraordinarily important to Diane to maintain control of herself and her own dignity during the time remaining to her […]. Knowing of her desire of independence and her decision to stay in control, I though this request made perfect sense.”

In another case, a family member stressed their mother’s lack of adaptation to the disease, due to a strong desire for control:

“One family member described her mother as ‘an extraordinarily independent person, absolutely needing to be in control of her life all the time and already felt—how shall I put it—she had problems with feeling not in control’” (Pearlman et al. 2005).

Finally, Ganzini et al. (2003) emphasized the desire for control as the main reason for wishing for death:

“So she was a control person. You know, we are talking big time control... You know, ‘I am in charge here.’ She sort of self-directed her medical care... It was a control issue, not a pain issue...’ I want to be in control of my destiny. I don’t want to go out as, you know, incontinent, in pain, crying, you know tearful person. I want to go out with some dignity.’”

IV. DISCUSSION

As Noblit and Hare (1988) point out, it is possible that after the analysis of data a theoretical (explanatory) model may emerge, one that integrates the results obtained on a higher level of abstraction. The systematic review carried out here identified three broad themes that together gave rise to a more dynamic theoretical model. This highlights how deeply the different themes and subthemes described above are blended together, interpenetrating with one another, such that in many of the quotes we have used as examples one is looking at the same phenomena from different angles. In terms of our explanatory model it can be seen how the experience of patients cannot be understood outside of their experience of illness, of the influence of the social context, or of the impact that their experience has on their sense of identity. A clear example of this is the fact that, when comparing the 21 studies, the loss of physical function linked to perceived dependency is the strongest mediator of a loss of perceived dignity. In this case, dependency cannot be separated from the loss of functionality, from the new social roles brought about by illness, or from the sense of a new identity marked by fear, uncertainty, anxiety and hopelessness, etc. In terms of the self-body-world axis it is clear that any change in one or more of the three components will affect the person's experience of the world.

This explanatory model also suggests that the notions of dignity and the lived body both refer to the person as a whole. From the position of phenomenology, the body is seen not only as an object capable of certain mechanisms defined in anatomical and physiological terms but also as something lived, subject to interpretation, experiences, emotions and desires, and situated in a specific world and culture. Qualitative studies of dignity show that any change in the particular "world" of the individual patient can affect his/her perception of dignity. This is why the qualitative perspective can provide important insights for clinical practice by giving a voice to the experience of patients, deepening our understanding of the other's world, and comprehending the body from a more complete point of view: that is, seeing it as a physical reality, as a field of localization of sensations, as the center of action, as the agent of free movement, as an obstacle, and so on.

Considering the person as an embodied subject (that is, as a whole) has numerous consequences for clinical practice. Toombs herself (1992; 2001) mentions some of them: communicating effectively with patients, understanding their physical symptoms, responding to their needs (especially when they do not correlate with physio-pathological findings) and to the experiential characteristics of the disease, recognizing and alleviating suffering and pain, and offering personalized responses (taking into account the fact that each person is unique and lives reality in a unique way) to the particular problems of those who seek help.

These practical implications suggested by Toombs are directly relevant to some of the limitations that patients express in relation to their illness, and which can be seen in each of the themes identified by our review. First, the loss of functionality was, in most cases, experienced in a negative way (as something that considerably undermined the person's perceived dignity). However, although the loss of functionality may be one factor that leads patients to experience their illness from the viewpoint of the objective, biological, mechanical or functional body, the recognition and understanding by others of their physical symptoms, suffering and pain could help to generate new attitudes and strategies for coping with illness from a more positive perspective; it may also help patients to feel that others have a better understanding of what it means to live with advanced illness.

Second, responding to the experiential characteristics of the disease may favor the development of interventions that seek to address the sense of lost identity, disintegration and loss of self or essence that some patients report. It is clear from the quotes we have used as examples that illness transcends the physio-pathological plane and this is something that not only patients but also relatives and health professionals need to be aware of so as to be able to address all aspects of the ill person's predicament. For physicians and nurses, addressing the experiential side of illness would entail the ability to offer personalized responses to a given individual's unique experience. In some of the quotes, for example, one can see how a lack of communication skills among some health professionals may impact negatively on a patient's sense of dignity. Thus, communicating effectively with patients and responding to their needs is essential for maintaining this social dignity.

Third, as noted above, disease represents a loss of control and autonomy, which in many cases leads to total dependence. However, this loss of control also draws attention to our inherent need for the help of others in order to live, and in fact highlights the relational nature of human beings. Thus, despite the painful experience of illness, some participants in studies of the end of life report that an awareness of their vulnerability represented a chance to restore ties with loved ones (cf. Toombs 1992, 111-112), to promote union with others (Lavery et al. 2001; Ho et al. 2013a; Ho et al. 2013b) and to see the living of one's final moments as an opportunity to transmit values to younger family members (Ho et al. 2013a; Ho et al. 2013b). In other words, dependence on loved ones may also provide an opportunity for healing, serving as a reminder that a sense of lived autonomy and control can also be gained by accepting the assistance and agency of those to whom we are closest. This contrasts with the narrower view of autonomy as equivalent to the independent actions of a separate self, something which, for these patients at least, would seem to be an unrealizable ideal.

V. CONCLUSION

Dignity, mediated by autonomy, control or self-determination, is, in the context of advanced illness, a dynamic and embodied phenomenon within the nexus formed by self-body-others-world. By analyzing this experience through quotations drawn from qualitative studies we have been able to show how patient-generated reports are best understood and organized from a phenomenological (rather than objectified) perspective. Indeed, a deeper exploration of the experiential context of patients at the end of life is one way through which they may come to be seen as more than just objective bodies, reduced to the circumstances of their illness. Given that the perception of dignity is influenced by many factors, developing care plans that are informed by a phenomenological perspective will help to safeguard the dignity of patients (and their families), thereby helping to ensure a better quality of life.

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NOTES

[i] See for example: Zaner, R. M. 1971. The Problem of Embodiment: Some Contributions to a Phenomenology of the Body. 2nd ed. La Haye: Martinus Nijhoff. Toombs, S. K. 1988. Illness and the Paradigm of the Lived Body. Theoretical Medicine and Bioethics 9 (2): 201–26. Toombs, S. K. 2004. Living and Dying with Dignity: Reflections on Lived Experience. Journal of Palliative Care 20 (3): 193–200. Toombs, S. K (ed.). 2001. Handbook of Phenomenology in Medicine. Dordrecht: Kluwer Academic Publishers. Toombs, S. K. 1992. The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician an Patient. Boston: Kluwer Academic. Leder, D. 1990. The Absent Body. Chicago: University of Chicago Press. Bolmsjö, Ingrid. 2000. "Existential Issues in Palliative Care-Interviews with Cancer Patients." Journal of Palliative Care 16 (2): 20. Alongside Toombs, the work of Havi Carel deserves special mention. Carel is creating a phenomenology of illness from her own experience as a sufferer of a lung disease (lymphangioleiomyomatosis).

[ii] An example of this 'écart' can be found in the well-documented cases of chronic pain in patients who present no observable cause at the physiological level that might account for their experience of pain.

[iii] This image used by Merleau-Ponty was first developed by Husserl in Ideas II.

[iv] Havi Carel also (2007) stated that the experience of disease may favor a reinterpretation of one's life in terms of “adaptability” and “creativity”: “gaining control, confronting loss, struggling for normalcy, reformulation of the self, transcending suffering and courage in the face of adversity.” Thus, it may be possible to achieve a more profound reconciliation between the biological body and the lived body after the disruption caused by illness.

[v] From a Heideggerian inspiration, the concept of alienation or estrangement (Unheimlichkeit) is one of the keys to the analysis made by Fredrik Svenaeus of the existential situation of being ill. (Cf. Svenaeus, F., 2001. Das unhemliche – Towards a phenomenology of illness. Medicine, Health Care and Philosophy 3: 3-16).

[vi] For an interesting approach to the Sartrean phenomenology of illness, see: Svaneus, F., 2009. The phenomenology of falling ill: an explication, Critique and improvement of Sartre’s theory of embodiment and alienation. Human Studies 32: 53-66.

[vii] The etymology of the word “object” (ob-iectus) illustrates clearly how an object is “a thing” of little value which can be thrown away (note the semantical proximity to ab-iectus).

[viii] In the Sartrean view, the act of looking at oneself as an object can only be done through the objectifying gaze of the other. It is knowing that I am being looked at, or may be looked at, that makes me aware of the objectuality of my body. In Sartre the objectifying gaze is the gaze of the other; or the gaze that takes place through the gaze of others: the feeling of being seen "like this" or "in another way" by the other.

[ix] “The Other is the indispensable mediator between myself and me. I am ashamed of myself as I appear to the Other. By the mere appearance of the Other, I am put in the position of passing judgment on myself as on an object, for it is as an object that I appear to the Other. Yet this object which has appeared to the Other is not an empty image in the mind of another […].I recognize that I am as the Other sees me. There is however no question of a comparison between what I am for myself and what I am for the Other as if I found in myself, in the mode of being of the For-itself, an equivalent of what I am for the Other […]. Thus the Other has not only revealed to me what I was; he has established me in a new type of being which can support new qualifications […]. Thus, shame is shame of oneself before the Other” (Sartre 1993 [1943], 222).

REFERENCES

Oregon Public Health Division. 2016. Oregon death with dignity act: 2015 data summary, https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf (accessed May 2, 2016).

Antiel, R. M., F. A. Curlin, K. M. James, D. P. Sulmasy, and J. C. Tilburt. 2012. Dignity in end-of-life care: results of a national survey of us physicians. Journal Pain Symptom Manage 44 (3): 331–39. doi:10.1016/j.jpainsymman.2011.09.020.Dignity.

Beauchamp, T. L., and J. Childress. 1979. Principles of biomedical ethics. Oxford: Oxford University press.

Bolmsjö, I. 2000. Existential issues in palliative care-interviews with cancer patients. Journal of Palliative Care 16 (2): 20-24.

Carel, H. 2007. Can I be ill and happy? Philosophia 35 (2): 95-110.

Cassell, E. J. 2001. The phenomenon of suffering and its relationship to pain. In: Handbook of Phenomenology and Medicine (pp. 371-90), S. K. Toombs (ed). Dordrecht: Kluwer Academic Publishers.

Chapple, A, and S Ziebland. 2006. What people close to death say about euthanasia and assisted suicide: a qualitative study. Journal of Medical Ethics 32 (12): 706–10. doi:10.1136/jme.2006.015883.

Chochinov, H. M., 2002. Dignity-conserving care-a new model for palliative care: helping the patient feel valued. JAMA 287 (17): 2253–60.

Chochinov, H. M. 2004. Dignity and the eye of the beholder. Journal of Clinical Oncology 22 (7): 1336–40. doi:10.1200/JCO.2004.12.095.

Chochinov, H. M. 2007. Dignity and the essence of medicine: The A, B, C, and D of Dignity Conserving Care. BMJ 335 (7612): 184–87. doi:10.1136/bmj.39244.650926.47.

Chochinov, H. M. T. Hack, S. McClement, L. Kristjanson, and Mike Harlos. 2002. Dignity in the terminally ill: a developing empirical model. Social Science and Medicine 54 (3): 433–43.

Chochinov, H. M., T Hassard, S. McClement, T. Hack, L. J. Kristjanson, M. Harlos, S. Sinclair, and A. Murray. 2008. The Patient Dignity Inventory: A novel way of measuring dignity-related distress in palliative care. Journal of Pain and Symptom Management 36 (6): 559–71. doi:10.1016/j.jpainsymman.2007.12.018.

Chochinov, H. M., L. J Kristjanson, T. Hack, T. Hassard, S. McClement, and M. Harlos. 2007. Burden to others and the terminally ill. Journal of Pain and Symptom Management 34 (5): 463–71. doi:10.1016/j.jpainsymman.2006.12.012.

Coyle, N., and L. Sculco. 2004. Expressed desire for hastened death in seven patients living with advanced cancer: A phenomenologic inquiry. Oncology Nursing Forum 31 (4): 699–709.

Emanuel, E. J., and L L Emanuel. 1998. The promise of a good death. Lancet 351: 21–29.

Enes, S. P., 2003. An exploration of dignity in palliative care. Palliative Medicine 17 (3): 263–69.

Escribano, X. 2013. Cos viscut (Leib). Anuari de la Societat Catalana de Filosofia 24: 135-154. doi: 10.2436/20.3001.01.30.

Franklin, L, B Ternestedt, and L Nordenfelt. 2006. Views on dignity of elderly nursing home residents. The Hastings Center Report 13 (2). doi:10.1191/0969733006ne851oa.

Ganzini, L., S. K. Dobscha, R. T Heintz, and N Press. 2003. Oregon physicians' perceptions of patients who request assisted suicide and their families. Journal of Palliative Medicine 6 (3): 381–90.

Guo, Q., and C. S. Jacelon. 2014. An integrative review of dignity in end-of-life care. Palliative Medicine 28 (7): 931–40. doi:10.1177/0269216314528399.

Haddock, Jane. 1996. Towards Further Clarification of the Concept 'Dignity.' Journal of Advanced Nursing 24 (5): 924–31.

Hall, A. C. 1996. To die with dignity: Comparing physician assisted suicide in the United States, Japan and the Netherlands. Washington University Law Quarterly 74 (3): 803–40.

Ho, A. H., P. P. Leung, D. M. Tse, S. M. Pang, H. M. Chochinov, R. A. Neimeyer, and C. L. Chan. 2013. Dignity amidst liminality: healing within suffering among Chinese terminal cancer patients. Death Studies 37 (10): 953–70. doi:10.1080/07481187.2012.703078.

Ho, A. H., C. L. Chan, P. P. Leung, H. M. Chochinov, R. A. Neimeyer, S. M. Pang, and D. M. Tse. 2013. Living and dying with dignity in Chinese society: Perspectives of older palliative care patients in Hong Kong. Death Studies 42 (4): 455–61. doi:10.1093/ageing/aft003.

Husserl, E. (1997 [1952]) Ideas relativas a una fenomenología pura y una filosofía fenomenológica. Libro II: Investigaciones fenomenológicas sobre la constitución. (Trans. Antonio Zirión Q.) México D.F.: Universidad Nacional Autónoma de México.

Jacelon, C. S. 2003. The dignity of elders in an acute care hospital. Qualitative Health Research 13 (4): 543–56. doi:10.1177/1049732302250762.

Jacobson, N. 2009. A taxonomy of dignity: a grounded theory study. BMC International Health and Human Rights 9: 3. doi:10.1186/1472-698X-9-3.

Johnson, P R. 1998. An analysis of ‘Dignity’. Theoretical Medicine and Bioethics 19 (4): 337–52.

Kade, W. 2000. Death with Dignity: A Case Study. Annals of Internal Medicine 132: 504–506.

Klinkenberg, M., D. L Willems, B. D Onwuteaka-Philipsen, D. J H Deeg, and G. van der Wal. 2004. Preferences in end-of-life care of older persons: after-death interviews with proxy respondents. Social Science and Medicine 59 (12): 2467–77. doi:10.1016/j.socscimed.2004.04.006.

Lavery, J. V., J. Boyle, B. M. Dickens, H. Maclean, and P. A. Singer. 2001. Origins of the desire for euthanasia and assisted suicide in people with HIV-1 or AIDS: A qualitative study. Lancet 358 (9279): 362–67.

Lavoie, M., D. Blondeau, and J. Picard-Morin. 2011. The Autonomy experience of patients in palliative care. Journal of Hospice and Palliative Nursing 13 (1): 47–53. doi:10.1097/NJH.0b013e318202425c.

Leung, D. 2007. Granting death with dignity: patient, family and professional perspectives. International Journal of Palliative Nursing 13 (4): 170–75.

Mak, Y.Y., and G. Elwyn. 2005. Voices of the terminally ill: Uncovering the meaning of desire for euthanasia. Palliative Medicine 19 (1): 343–50.

McNamara, B. 2004. Good enough death: Autonomy and choice in australian palliative care. Social Science and Medicine 58 (5): 929–38. doi:10.1016/j.socscimed.2003.10.042.

Mesler, M. A., and P J Miller. 2000. Hospice and assisted suicide: The structure and process of an inherent dilemma. Death Studies 24 (2): 135–55.

National Institutes of Health. 1979. The Belmont Report Ethical Principles and Guidelines for the Protection of Human Subjects of Research.

Noblit, G, and R. Hare. 1988. Meta-Ethnography: Sinthesizing qualitative studies. Newbury Park: Sage.

Onwuteaka-Philipsen, B. D., A. Van Der Heide, D. Koper, I. Keij-Deerenberg, and J. A C. Rietjens. 2003. Public health euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995, and 2001. The Lancet 632 (9381): 395–99.

Östlund, U., H. Brown, and B. Johnston. 2012. Dignity Conserving care at end-of-life: a narrative review. European Journal of Oncology Nursing 16 (4): 353–67. doi:10.1016/j.ejon.2011.07.010.

Pearlman, R. A., C. Hsu, H. Starks, A. L. Back, J. R. Gordon, A. J. Bharucha, B. A. Koenig, and M. P. Battin. 2005. Motivations for physician-assisted suicide. Journal of General Internal Medicine 20 (3): 234–39. doi:10.1111/j.1525-1497.2005.40225.x.

Periyakoil, V. S., H. C. Kraemer, and A. Noda. 2009. Creation and the empirical validation of the dignity card-sort tool to assess factors influencing erosion of dignity at life’s end. Journal of Palliative Medicine 12 (12): 1125–30. doi:10.1089=jpm.2009.0123.

Pleschberger, S. 2007. Dignity and the challenge of dying in nursing homes: The residents’ view. Age and Ageing 36 (2): 197–202. doi:10.1093/ageing/afl152.

Proulx, K. 2004. “Dying with Dignity: The good patient versus the good death. American Journal of Hospice and Palliative Medicine 21 (2): 116–20. doi:10.1177/104990910402100209.

Pullman, D. 1996. Dying with dignity and the death of dignity. Health Law Journal 4: 197–219.

Quill, T. E. 1991. Death and dignity-a case of individual decision making. New England Journal of Medicine 324 (10): 691–94.

Rodríguez-Prat, A., C. Monforte-Royo, J. Porta-Sales, X. Escribano, and A. Balaguer. 2016. Patient perspectives of dignity, autonomy and control at the end of life: systematic review and meta-ethnography. PLoS ONE 11 (3): e0151435. doi:doi: 10.1371/journal.pone.0151435.

Sartre, Jean-Paul. (1993 [1943]). El ser y la nada [trans: Juan Valmar]. Barcelona: Altaya.

Schroepfer, T. A., H. Noh, and M. Kavanaugh. 2009. The myriad strategies for seeking control in the dying process. The Gerontologist 49 (6): 755–66. doi:10.1093/geront/gnp060.

Street, A. F., and D. W. Kissane. 2001. Constructions of dignity in end-of-life care. Journal of Palliative Care 17 (2): 93–101.

Sulmasy, D. P. 2005. Death, dignity, and the theory of value. Ethical Perspectives 9 (2): 103–30. doi:10.2143/EP.9.2.503850.

Sulmasy, D. P.. 2013. The varieties of human dignity: a logical and conceptual analysis. Medicine, Health Care, and Philosophy 16 (4): 937–44. doi:10.1007/s11019-012-9400-1.

Toombs, S. K. 1988. Illness and the paradigm of the lived body. Theoretical Medicine and Bioethics 9: 201-226.

Toombs, S. K. 1992. The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physician an Patient. Boston: Kluwer Academic.

Toombs, S. K., (ed.) 2001. Handbook of Phenomenology in Medicine. Dordrecht: Kluwer Academic Publishers.

United Nations. 1948. Universal Declaration of Human Rights, http://www.ohchr.org/EN/UDHR/Pages/Language.aspx?LangID=eng (accessed May 2, 2016).

Veldink, J. H., J. H. J. Wokke, G. van der Wal, J. M. B. V. Jong, and L. H. van den Berg. 2002. Euthanasia and physician-assisted suicide among patients with amyotrophic lateral sclerosis in the Netherlands. New England Journal of Medicine 346 (21): 1638–44. doi:10.1056/NEJMsa012739.

Vig, E. K., and R. A. Pearlman. 2004. Good and bad dying from the perspective of terminally ill men. Archives of Internal Medicine 164 (9): 977–81. doi:10.1001/archinte.164.9.977.

Vladeck, B. C., and E. Westphal. 2012. Dignity-driven decision making: A compelling strategy for improving care for people with advanced illness. Health Affairs 31 (6): 1269–76. doi:10.1377/hlthaff.2012.0173.

Vlug, M. G., H. C. W. de Vet, H R. W. Pasman, M. L. Rurup, and B. D Onwuteaka-Philipsen. 2011. The development of an instrument to measure factors that influence self-perceived dignity. Journal of Palliative Medicine 14 (5): 578–86. doi:10.1089/jpm.2010.0513.

Volker, D. L, D. Kahn, and J. H Penticuff. 2004a. Patient control and end-of-life care part ii: the patient perspective. Oncology Nursing Forum 31 (5): 954–60.

Volker, D. L, D. Kahn, and J. H Penticuff. 2004b. Patient control and end-of-life care. Part I: The advanced practice nurse perspective. Oncology Nursing Forum 31 (5): 954–60.

Walsh, K, and I. Kowanko. 2002. Nurses’ and patients' perceptions of dignity. International Journal of Nursing Practice 8 (3): 143–51.

White, M., and D. Callahan. 2000. Oregon’s first year: the medicalization of control. Psychology, Public Policy, and Law 6 (2): 331–41. doi:10.1037//1076-8971.6.2.331.

Tercer artículo: Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography

Presentación del tercer estudio de esta tesis:

En el año 2017 se cumplen 5 años de la publicación de ‘What Lies behind the Wish to Hasten Death? A Systematic Review and Meta-Ethnography from the Perspective of Patients’ (Monforte-Royo et al., 2012), el primer estudio de síntesis de las experiencias de pacientes en contextos de final de vida que habían manifestado DAM. Una de las limitaciones que los autores de este estudio reconocieron, fue que en los artículos incluidos no había representatividad de países europeos. También se incluyó un estudio llevado a cabo en un hospice chino que había seguido el modelo inglés por lo que no quedaba claro si, el modelo explicativo del DAM podría ser generalizable a poblaciones de países no occidentales.

Desde entonces, siete estudios sobre la experiencia del DAM desde la perspectiva de los propios pacientes se han llevado a cabo de los cuales, seis proceden de países europeos (Alemania, Holanda y Suiza) y uno de Tailandia. El hecho de que estos estudios hubieran sido realizados en los países mencionados tiene un especial interés puesto que en Holanda y Suiza la práctica de la eutanasia y el suicidio asistido están despenenalizas y Tailandia es un país donde el contexto cultural y social es totalmente distinto respecto al resto de países incluidos.

De forma paralela, recientemente un equipo de investigación de la Universidad de Stirling, liderado por la Dra. Emma France ha publicado un protocolo para la actualización de meta-etnografías (2015; 2016). Hasta el momento, la actualización de síntesis de estudios cualitativos es una práctica bastante novedosa pero, en efecto, tal y como afirman los promotores de estas guías, puede ser una herramienta valiosa para aportar evidencia sobre las creencias, experiencias y comprensión del mundo de los pacientes y profesionales de la salud respecto a temas complejos (France et al., 2016). De esta forma, partiendo de los avances que se han dado en la conceptualización del DAM y teniendo en cuenta la existencia de los nuevos estudios cualitativos realizados en contextos totalmente distintos a los de los incluidos en la revisión anterior, nos propusimos actualizar la meta-etnografía original siguiendo las orientaciones metodológicas propuestas por France et al. (2016)

Asimismo, el equipo de la Dra. France ha impulsado un proyecto para consensuar entre expertos, una guía práctica para la realización de meta-etnografías siguiendo el modelo de Noblit y Hare[46]. Con motivo de la publicación de 'Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography' (Rodríguez-Prat et al., 2016) –y gracias al contacto de la Dra. Monforte– pude formar parte del grupo de expertos para el consenso de esta metodología sobre meta-etnografías a través de un estudio que seguía el método Delphi.

Por último, este tercer artículo cuenta con la colaboración valiosa del Dr. Andrew Booth, académico de referencia internacional experto en revisiones sistemáticas, síntesis sobre la práctica clínica basada en la evidencia y metodología cualitativa. Tiene más de dos centenares de publicaciones y ha participado en numerosos proyectos de investigación[47].

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[46] eMERGe Project - a study Developing Meta-Ethnography Reporting Guideline and standards for research.

[47] Para más información ver www.sheffield.ac.uk/scharr/sections/ir/staff/booth_a (Acceso 18 Abril 2017).

Title: Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography

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Abstract

Objectives: Patients with advanced disease sometimes express a wish to hasten death (WTHD). In 2012 we published a systematic review and meta-ethnography of qualitative studies examining the experience and meaning of this phenomenon. Since then, new studies eligible for inclusion have been reported, including in Europe, a region not previously featured, and specifically in countries with different legal frameworks for euthanasia and assisted suicide. The aim of the present study was to update our previous review by including new research and to conduct a new analysis of available data on this topic.

Setting: Eligible studies originated from Australia, Canada, China, Germany, The Netherlands, Switzerland, Thailand, and USA.

Participants: Studies of patients with life-threatening conditions that had expressed the WTHD.

Design: The search strategy combined subject terms with free-text searching of PubMed MEDLINE, Web of Science, CINAHL and PsycInfo. The qualitative synthesis followed the methodology described by Noblit and Hare, using the "adding to and revising the original" model for updating a meta-ethnography, proposed by France et al. Quality assessment was done using the Critical Appraisal Skills Programme checklist.

Results: 14 studies involving 255 participants with life-threatening illnesses were identified. Five themes emerged from the analysis: suffering (overarching theme), reasons for and meanings and functions of the WTHD, and the experience of a timeline towards dying and death. In the context of advanced disease, the WTHD emerges as a reaction to physical, psychological, social and existential suffering, all of which impacts on the patient's sense of self, of dignity and meaning in life.

Conclusions: The WTHD can hold different meanings for each individual; serving functions other than to communicate a genuine wish to die. Understanding the reasons for, and meanings and functions of, the WTHD is crucial for drawing up and implementing care plans to meet the needs of individual patients.

Strengths and limitations of this study

- This updated review and synthesis of the published literature on the WTHD offers a more nuanced understanding of the phenomenon.
- The review provides meta-ethnographic analysis of 14 studies which recorded, the experiences of 255 participants from different cultural backgrounds including Australia, Canada, China, Germany, Switzerland, Thailand, The Netherlands and the USA.
- This synthesis highlights suffering as an overarching theme and includes physical, psychological, social or existential factors.
- The synthesis exemplifies a new approach to the updating of syntheses of qualitative research.
- Included studies offer different conceptualizations of the WTHD with the research objectives of some studies only touching indirectly upon the phenomenon.

Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography

INTRODUCTION

Few issues in modern society generate as much controversy as euthanasia, and assisted suicide (EAS) among people facing an advanced illness. Across the world, opinions, and attitudes towards this issue differ widely. Debate, however, often centres around the implications for society or the existing legal framework. What is often overlooked is the common thread that links all those persons who contemplate ending their life: the desire to die or to hasten their death. Why do some patients with advanced disease wish to hasten their death? What meaning does this wish hold for them? What is the experience of a person who feels such a wish? To what extent do commonalities exist among those who come to feel this wish?

Although the desire to die has traditionally been seen to result from physical suffering, research suggests that this explanation is reductionist (1), and that such a wish must be understood in the context of patient experience. Thus, while cross-sectional studies offer valuable information about what may trigger a wish to die, the fluctuating, ambivalent, subjective, and complex nature of such wishes requires a more detailed examination of patients' experiences.

Several qualitative studies have explored the wish to die in patients with advanced disease highlighting the important role played by psychosocial, and existential/spiritual factors, alongside physical symptoms (2,3). Thus, factors such as loss of self, loss of the sense of dignity, loss of autonomy, fear about the future, fear of suffering, and fear of being a burden to others are reported among the main triggers of a wish to hasten death (WTHD). Interpretative analysis of the WTHD suggests that, in addition to these potential motivations, attention must focus on the meanings, functions, and intentions that underlie the expression of a WTHD. Thus, if we are to understand what patients actually mean when they say that they ‘no longer wish to live in this way’ we must explore their personal history, attitudes, beliefs, and thoughts. Furthermore, it is important not to confuse, for example, a wish to die in someone who is not considering actually hastening his/her death with a will to die in someone who takes action towards dying (4).

In 2012 our group published a systematic review, and interpretative synthesis (5) of then-published qualitative studies of the WTHD in seeking to understand the experience of patients with serious or incurable illness who expressed such a wish. The synthesis included studies conducted in Canada (1,6), Australia (2), China (7), and the USA (8). At that time, however, no such studies were identified from European countries.

Five years on, the subsequent publication of qualitative studies of the WTHD, among similar patient groups, and in different contexts to those featured in our earlier synthesis, justifies the need for an updated systematic review. In addition, the possibility of including studies from European countries in which EAS have been decriminalised (4,9–11) enables us to explore the extent to which different legal contexts influence the expression of a WTHD. The aim of the present study was therefore to provide an updated review of knowledge regarding the WTHD (understood here as any expression of the desire to die in patients affected by a life threatening condition), taking into account possible contextual differences.

METHODS

This systematic review, and interpretative synthesis updates our previous synthesis (5) that included studies from 2001 to January 2010. In seeking to incorporate recent research within the synthesis, we extended our bibliographic search to cover the period from December 2000 to January 2016. The update employs Noblit and Hare’s (12) meta-ethnography method, the aim of which is “to compare, re-interpret, and synthesise the findings (i.e. authors’ concepts, and themes) of separate qualitative studies to arrive at an exhaustive description of the range, nature, and variety of patients’ experiences” (13). This method was chosen given its widespread use in health-related research (14).

France et al. (15) propose various models for updating meta-ethnographies, using the analogy of house-building. This review applies the model they refer to as ‘extending and renovating the original house’ (i.e. adding to and revising an existing meta-ethnography). France et al. (15) outline potential advantages of using this model: the output forms a single coherent model or set of findings, rather than two, increasing its potential usefulness; it can lead to new conceptual insights; and it allows for innovation within the updated analysis/synthesis, while making efficient use of resources expended on the original meta-ethnography.

Data sources and search strategy

In seeking recent clinical evidence about the WTHD we revised our original search strategy to optimise the trade-off between sensitivity, and specificity (see Table-S1). Relevant MeSH, and free-text terms were identified, and combined. The strategy was run in PubMed, CINAHL, Web of Science, and PsycINFO with the terminology being adapted to each database.

A filter for qualitative studies was used in PubMed (16), CINAHL (17), and PsycINFO (18). The qualitative PubMed filter was adapted to the specific language used by Web of Science.

Inclusion and exclusion criteria

To be included, papers had to report primary qualitative studies (i.e. studies using recognised methods of both qualitative data collection, and qualitative data analysis) written in English, and focusing on the expression of the WTHD in patients with life-threatening conditions. Paediatric populations were excluded, as were studies focusing on older populations in the absence of advanced disease.

One researcher carried out the systematic literature search, which was verified by another researcher. Screening involved selection of retrieved citations by title, abstract, and full text. The entire sample was double-reviewed. Disagreements were resolved by discussion within the research team. Figure 1 shows the PRISMA flowchart for the selection of studies.

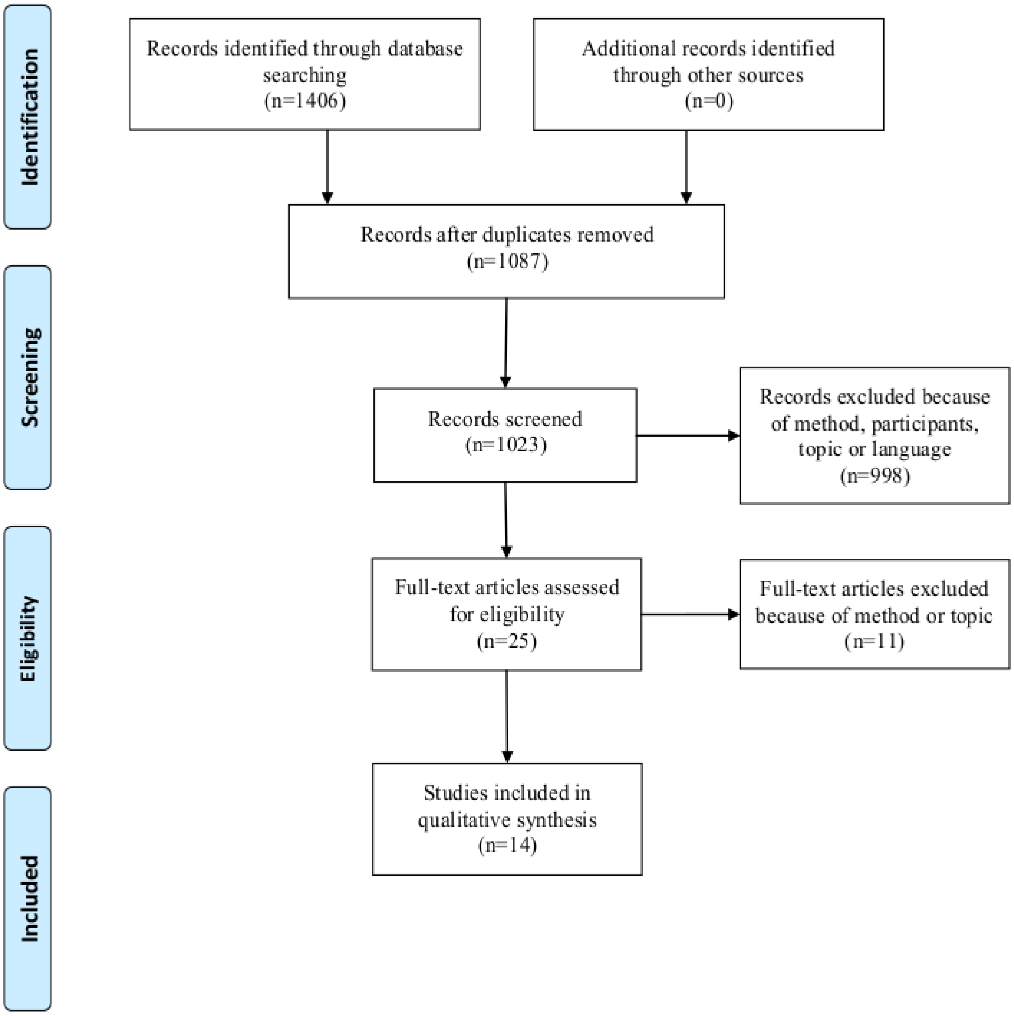

Figure 1. PRISMA flow diagram for study selection.

Critical appraisal

Included studies were assessed for methodological quality, and rigour using Critical Appraisal Skills Programme (CASP) guidelines for qualitative studies (19) (Table-S2). No studies were excluded from this review based on their quality.

Data analysis and synthesis

The synthesis followed the seven steps proposed by Noblit and Hare (12) as follows:

1) Definition of the research question: What is the experience of the wish to hasten death expressed by people with advanced illness?

2) A literature search for references to studies for inclusion in the synthesis.

3) Reading the studies in order to identify key and secondary concepts in each of them.

4) Determining how the studies are related. To this end we created a chart showing the categories that emerged from the studies (more descriptive level), and this served as the basis for abstracting themes and sub-themes from each study (more abstract levels that encapsulate the categories found in the different studies).

5) To perform translation across studies, in other words, to 'deconstruct' the studies, identifying different metaphors or concepts on the basis of words or statements in the original articles.

6) These translations were synthesized, to generate different levels of themes, sub-themes and final categories.

7) Presentation of the synthesis of the studies included, thus giving rise to a global understanding of the phenomenon and a response to the research question posed at the outset.

Supplementary Table-S3 juxtaposes the steps from the previous, and the updated meta-ethnography, and supplementary Table-S4 shows the comparison of yield between the original review, and the updated review. Atlas.ti 7 software was used to code, and memo significant statements to facilitate comparison of the themes, and categories obtained by each researcher.

RESULTS

Fourteen articles were included in the updated meta-ethnography [seven from the original synthesis (2001-January 2010) plus seven additional recent studies (2010-February 2016)] (Table 1). Of the seven new studies included, six were conducted in European settings (4,9–11,20,21), and one in Asia (22).

Three studies used grounded theory (1,6,20), with a further study using a modified approach (21). One was a mixed-method study (2), from which only the qualitative results were included in the present analysis. One study reported using a phenomenological approach (2), and three a combination of phenomenological, and hermeneutical methods (4,7,11). A hermeneutical-ethical approach was applied in one study (10). The design of one qualitative study was unclear (not specified) (22). Most studies used in-depth or semi-structured interviews to collect data, except for one that used narrative interviews (10). Sample sizes ranged from 2 to 35 participants, yielding a total sample of 255 patients (excluding the relatives interviewed in one study (23)). The majority of studies aimed to explore the WTHD as expressed by patients with advanced disease. Only two studies had the main objective of describing suffering (9,22).

Source paper	Country	Participants	Setting	Country's legislation on euthanasia and AS
Lavery et al. (1)	Canada	31 men; 1 woman with HIV/AIDS	HIV Ontario Observational Database	Neither euthanasia nor AS are legal
Kelly et al. (2)	Australia	30 terminally ill cancer patients	Inpatient hospice unit and home PC service	
Coyle and Sculco (24)	USA	7 terminally ill cancer patients	Pain and PC unit in an urban cancer research centre	
Mak and Elwyn (7)	China	6 patients	26-bed hospice in China.	
Pearlman et al. (23)	USA	35 patients	Patient advocacy organizations that counsel persons interested in AS, hospices and grief counsellors	AS legal since 2009. At the time of the study, AS had yet to be decriminalised
Schroepfer (8)		18 terminally ill elders	2 PC programmes, 2 hospital outpatient clinics and 6 hospices	Neither euthanasia nor AS are legal
Nissim et al. (6)	Canada	27 ambulatory cancer patients	Outpatient clinics at a large cancer centre	
Stiel et al. (20)	Germany	10 inpatients and 2 outpatients of PMD	PMD of 3 university hospitals	
Dees et al. (9)	The Netherlands	31 patients with different diagnoses	Support and Consultation on Euthanasia in The Netherlands network; hospice, hospital and nursing home	Euthanasia and AS legal since 2009
Ohnsorge et al. (10)	Switzerland	2 women with terminal cancer, and caregivers	PC hospice	AS legal since 1942
Ohnsorge et al. (11)		30 terminally ill cancer inpatients/outpatients, and their caregivers/relatives	Hospice, a PC ward in the oncology department of a general hospital & an ambulatory PC service	
Ohnsorge et al. (4)		30 terminally ill cancer inpatients/outpatients, and their caregivers/relatives	Hospice, a PC ward in the oncology department of a general hospital & an ambulatory PC service	
Nilmanat et al. (22)	Thailand	11 women & 4 men with terminal cancer and short life expectancy	Public health service for cancer treatment	Neither euthanasia nor AS are legal
Pestinger et al. (21)	Germany	10 inpatients and 2 outpatients of PMD	PMD of 3 university hospitals	

*PMD: Palliative Medicine Department
*PC: Palliative Care

Table 1. Characteristics of the studies included in the present review

Description of themes

Five main themes emerged from the analysis of the WTHD expressed by patients with advanced disease: *suffering*, which appeared as an overarching theme; *reasons* for the WTHD; *meanings* of the WTHD; *functions* of the WTHD; and *lived experience of a timeline toward dying and death*. Supplementary Table-S5 shows the most representative statements for each theme together with its corresponding sub-themes.

The greater detail offered by the seven recent studies enabled the six themes from our previous meta-ethnography (5) to be subsumed under new, broader categories, without substantially changing their content (Table 2). One new theme emerged from the present analysis: *lived experience of a timeline toward dying and death.* Table 3 shows which themes, and sub-themes were present in each included study.

Themes from the original meta-ethnography (5)	Themes in the updated meta-ethnography	
WTHD in response to physical/psychological/spiritual suffering	Reasons for the WTHD	Suffering
Loss of self		
Fear		
WTHD as a desire to live but ‘not in this way’	Meanings of the WTHD	
WTHD as a way of ending suffering		
WTHD as a kind of control over life: ‘to have an ace up one’s sleeve just in case’	Functions of the WTHD	
	Lived experience of a timeline toward dying and death	

Table 2. Reclassification of themes from the original meta-ethnography in the present, updated meta-ethnography

	Lavery et al. (1)	Kelly et al. (2)	Coyle and Sculco (24)	Mak and Elwyn (7)	Pearlman et al. (23)	Schroepfer (8)	Nissim et al. (6)	Stiel et al. (20)	Dees et al. (9)	Ohnsorge et al. (10)	Ohnsorge et al. (11)	Ohnsorge et al. (4)	Nilmanat et al. (22)	Pestinger et al. (21)
Suffering	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Reasons for the WTHD														
Physical factors	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Psychological factors	✓	✓	✓	✓	✓	✓	✓	-	✓	-	✓	✓	✓	✓
Social factors	✓	✓	✓	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	✓
Loss of self	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Meanings of the WTHD														
Cry for help	✓	✓	✓	✓	✓	✓	✓	-	✓	-	✓	✓	✓	-
To end suffering	✓	-	✓	✓	✓	✓	✓	-	✓	-	✓	✓	✓	✓
To spare others from the burden of oneself	✓	✓	✓	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	-
To preserve self-determination to the very end	✓	-	✓	✓	✓	✓	✓	-	✓	-	✓	✓	✓	✓
Will to live but not in this way		-	✓	✓	✓	✓	✓	-	✓	✓	✓	✓	✓	-
Functions of the WTHD														
WTHD as a means of communicating		-	✓	-	-	-	-	-	-	-	-	✓	-	-
WTHD as a form of control	✓	-	✓	✓	✓	✓	✓	-	✓	✓	✓	✓	✓	✓
Lived experience of a timeline toward dying and death	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Table 3. Themes and sub-themes present in each of the studies included in this review

1. Suffering

Suffering emerged as an overarching theme, confirming that the WTHD in people with advanced disease cannot be understood without taking their suffering into account. As a theme, suffering referred not only to physical distress (especially pain) but also to psychological, social or existential aspects. Thus, suffering was a complex, and multidimensional phenomenon affecting the whole person, having physical repercussions, and impacting both on their identity, and their relationships with all aspects of their immediate environment. Suffering was a common denominator for understanding the other four themes: *reasons, meanings, functions,* and *lived experience of a timeline toward dying and death.*

> "To have pain and also breathlessness, that would be terrible and so much suffering. My breathing is suffering and this affects my appetite. So many kinds of suffering… The social situation is suffering…" (7).

2. Reasons for the WTHD

This theme refers to the factors or rational motivations that led to a WTHD being expressed. As in our previous review (5), the WTHD emerged as a complex reaction to suffering that was related to all dimensions of personhood. Our analysis indicated that the theme *reasons* could be broken down into four sub-themes: *physical, psychological/emotional* and *social factors*, and the *loss of self.*

Physical factors

In all the studies reviewed, *physical factors* (symptoms) were a key issue leading to the WTHD. Participants particularly emphasised a loss of function, and pain, although aspects such as fatigue, dyspnoea, incontinence, and cognitive impairments were also mentioned as producing considerable distress (1,4,9,23).

Most participants referred to the loss of physical function; their illness prevented them from doing the things they once did, stripping them of their independence: "I lost my dignity, lying in bed in diapers, I am no longer the independent person I used to be" (9). The loss of function was also linked to a diminished quality of life.

Many patients described severe, and unbearable pain as a factor that triggered a WTHD. Pain "affected the wholeness of their beings" (22), and their lived experience:

"pain affects everything. It makes you tired. It affects how you can eat. It affects other people, and the fact is that even if you try to hide it, you can't. […] pain takes that life out of you". Some patients experienced intense, and uncontrollable pain, but stated that were it not for this they would want to go on living: "It is torturous... thinking when I am going to die to escape from this suffering. But when I am not in pain, I want to live. When the symptoms disappear, I want to continue living, as I do not want to depart from my loved ones" (22). Likewise, some participants (9) stated that their request for euthanasia stemmed from the continuous pain they suffered. In many cases, they feared becoming a burden on others, and making them suffer. For others, however, it was linked to a loss of control over their illness (due to ineffective medical treatment), and to a feeling of helplessness, to the sense that nothing could remedy their situation.

Psychological/emotional factors

This sub-theme comprised two categories: *fear,* and *hopelessness*. Fear was expressed in most interview studies, encapsulating fear due to uncertainty, fear about future suffering, and fear of the dying process.

Fear due to uncertainty was linked to inadequate knowledge about prognosis, and to not knowing what lay ahead. In most cases, fear was associated with a loss of control over bodily functions, and over one's life and circumstances, as well as with physical, and functional decline, and the thought of becoming a burden on family.

Many patients, aware of their progressive deterioration, foresaw a death that would be painful both for them, and their relatives, and hence they experienced a fear about future suffering. The experience of pain, and distress, combined with a loss of function, led some to expect an unbearable suffering 'worse than death itself' (9,21,23,24). In some interviews, pain or suffering was explicitly mentioned as "the biggest fear" (24). Some reported that they would rather die than suffer further pain of the kind they had already experienced.

The fear of the dying process resulted from patients' expectation that they would be unable to express their needs, wishes or problems due to frailty or cognitive impairment (21). This fear was linked to not knowing whether the future would be marked by intense suffering.

The sense of hopelessness felt by patients was associated with the progressive nature of their illness, a process that would lead inevitably to death, and about which nothing could be done: "You lie in bed and none of the normal functions come back. They will never come back and it will only get worse" (9). Some patients said they felt mentally exhausted, and tired of fighting their illness. One of the interviewees described his illness as "the end of many dreams for plans […] the end of it all. There's no future really" (2).

Social factors

For many, *social factors*, such as being a burden on others, making loved ones suffer, or being dependent, and in need of help, were another cause of suffering, and a reason for expressing the WTHD. The idea of causing others to suffer frequently caused patients themselves to suffer. For some, observing their own deterioration, and the impact of this on loved ones, was more difficult to bear than their own suffering.

Related to loss of function was increased dependency on others resulting from a deteriorating state. In some cases this dependency left many patients "at the mercy of others" (9), and feeling useless. Participants complained about needing to be fed, washed or dressed by others (1,7): "It's horrible […] the whole situation. […] Not being able to get out of it, and every morning the same thing: waking up, being washed, lying there till the evening, the same pain" (4). For those who had been highly independent prior to their illness, or who had a high level of professional responsibility at work, the change in role (i.e. to dependency, and vulnerability) impacted enormously on their way of life, with some finding this difficult to accept.

Some patients said that they felt devalued, and treated as if they were no longer a person. Thus, further suffering, and a loss of self-esteem could be caused by health professionals failing to respond to their needs, to convey empathy, and a comforting attitude, or to respect their treatment choices (4).

"Just one sentence can hurt me, making things even worse… Really bad… When I need someone to help me, they just hurt my self-esteem […] I was right but they said I was wrong... What was worst was that I had to admit to being wrong and agree with them" (7).

Loss of self

Many participants attributed the WTHD to a perceived loss of self or of identity, due to the impact of their illness on their life. Physical, psychological, and social factors (suffering; dependency; loss of control, both mentally, and physically; loss of self-esteem; or feeling a burden on others, etc.) combined to severely undermine their self-image, their sense of who they were: "she was going to lose significant ability to be the person she was" (23). Some studies referred to the loss of self as a loss of the essence, loss of personality, loss of the sense of dignity (23) or destruction of the self (24). When participants felt vulnerable, looked down on or inferior with respect to others, then the loss of self was heightened. In some cases, this led the individual to feel a loss of community (1), that is, a loss of close personal relationships accompanied by feelings of isolation, and a lack of understanding.

Many patients described the experience of being devalued or treated as an object, as well as the feeling of having lost control over oneself, and of being forced into a situation that went against all they considered to be important, as losing their sense of dignity. Some situations -especially those that drew attention to their loss of control, and independence, notably in hospital settings- were perceived by interviewees as demeaning, leading them to being felt treated as objects or patients rather than as individuals (1,23).

Some patients did not wish to succumb to a situation over which they had little control, and thus the WTHD emerged in response to a perceived lack of purpose or meaning in life: “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. […] 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” (6). For patients such as this, losing what made life worthwhile, and relevant strips them of the will to live. This loss of self is associated with a broader series of losses (of quality of life, of autonomy, of the ability to perform daily life activities, etc.), such that illness is experienced as progressive loss that will cease only in death.

3. Meanings of the WTHD

Our analysis suggested that the meanings attributed by patients to the WTHD could be categorised into five sub-themes.

Cry for help

As a result of their suffering, many participants expressed the need for immediate action to put an end to their torture, to the misery of the current situation (24). In some cases this involved an explicit request for help -whether from professionals or someone close to them- in coping with all they were going through. For other patients, the cry of despair was the result of their suffering, and the difficulty of accepting their illness, an aspect revealed in the rhetorical questions that are sometimes posed: ‘Why me?’ or ‘Why do I have to go through this?’ (22,24).

To end suffering

Death was sometimes described as preferable to suffering, or as the lesser of two evils (4) (“I don’t want to go through the dying process so I’ll kill myself” (24)). Here, the WTHD becomes synonymous with not wanting to suffer any more, and the desired death is seen as a release (“a vehicle to just, just stop my life” (24)), as a way of putting an end to loneliness, fear, dependence, pain, hopelessness, and the feeling that life is no longer enjoyable (8), or as a means of limiting disintegration, and loss of self (1).

To spare others from the burden of oneself

Advanced illness, and its consequences (i.e. suffering, loss of independence, the need for help from others) led some people to state that they would rather die than be a burden to their loved ones, or see them suffer: “No matter how much they love you, you are always a burden. You automatically become a burden to everyone…” (6); “When I know that my life has become a burden to my loved ones, I would rather die” (22). The WTHD can thus represent the desire to spare others from suffering, a gesture of altruism (24).

To preserve self-determination to the very end

The WTHD was also seen as a way of preserving self-determination, autonomy or control through to the very end of life. For some patients, the possibility of putting an end to their life, and of exerting some control, became more important as they began to lose more of their capacities.

“I will do things my way and to 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 will be, will be done my way. I will always be in control” (23).

“I am in control of this body […] I will do whatever I want to with it” (23).

“I would like to bring about my own death” (11).

Will to live, but not in this way

The WTHD also emerged, somewhat paradoxically, as an expression of “the will to live, but not in this way”. For some people, not being able to do the things that brought meaning, and value to their life was a reason to wish for its end. Many patients mentioned activities that made life worth living (e.g. creative activities, reading, driving, or enjoying time spent with family, and friends), and they felt convinced that when they could no longer do any of those things, their life would be meaningless, and they wouldn’t want to live anymore (23). Some participants referred explicitly to the paradox of a will to live but not in this way, acknowledging, for example, that they experienced a wish to die at the same time as undergoing active anti-cancer treatment (10).

4. Functions of the WTHD

Analysis of the reviewed studies suggested that the WTHD can serve two possible purposes or functions: *a means of communicating,* and *a form of control*.

WTHD as a means of communicating

Although many participants did not refer to this aspect explicitly, the expression of a WTHD served to communicate feelings, thoughts, and wishes. In the context of extreme suffering it represented a 'cry for help'. In some studies patients used the WTHD to voice concerns about death, and illness (4,24). One patient spoke about how difficult it was to talk about death with her husband, adding that the verbalisation of her WTHD had opened a way into this topic (4).

WTHD as a form of control

For some patients, having a sense of their own personal agency brought some relief from present suffering. In this respect, the WTHD was equated with maintaining some control over their life, and of avoiding further suffering. In some cases, this control was expressed through hypothetical plans about how they would end their life if things deteriorated. Coyle and Sculco (24) refer to this projection into the future as the 'if-then' scenario: if my illness progresses, and I can no longer bear to suffer, then I will put an end to my life. In countries where euthanasia or assisted suicide are legal, this notion of 'having a plan' implied making contact with organisations, or professionals that supported such practices (1,4,9,23).

5. Lived experience of a timeline toward dying and death

The experience of a WTHD was also associated with the sense that time was running out. The anticipation of imminent death, and an awareness of the finality of life brought more suffering, and disquiet, and it was in this context that, paradoxically, the idea of hastening one's death came to be seen as a way of putting an end to suffering. Some participants described how they had had to give up the usual things they did (4,23). Such inactivity left them feeling that all they could do was wait as time itself appeared to slow: "waiting and waiting, too often, extended, prolonged, so long, on and on, it should be over, limited, until the last moment, and from one second to another" (21).

For some people, their WTHD fluctuated over time. In these cases, the wish to live might become stronger as reasons why the person had wished to die became less prominent (e.g. their physical pain lessened). However, the balance could then tip the other way depending on their circumstances, such that, at times, a wish to die, and a wish to live might both be present.

DISCUSSION

Five years on from our previous meta-ethnography the inclusion, and analysis of seven additional studies has brought greater understanding of the WTHD. Using an approach that France et al. (15) refer to as 'extending and renovating the house' the inclusion of recent literature has enabled us to reclassify categories from our original synthesis into a new set of themes. The new analysis also yielded an additional theme not present in the earlier review. Statements from participants in the additional studies, as well as theorisation proposed by study authors, were key to this reconceptualization.

Our findings indicate that the primary, overarching theme for an understanding of the WTHD in patients with advanced disease is suffering. This extends to different dimensions of their personhood, and thus may involve physical, social, psychological/emotional, and/or spiritual/existential suffering. Many patients referred to the deep impact of this suffering on their sense of self or identity, as well as on their immediate surroundings, and their ways of coping with life. These findings are consistent with a recent international expert consensus statement, which defined the WTHD as "a reaction to suffering, in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate his or her death" (25).

Although suffering emerged as the common theme underlying the experience of the WTHD, one participant in the study by Ohnsorge et al. (4) stated that she was not suffering, but because she knew that she would die soon, she wanted death to come faster (without actually having the WTHD). While this is the only case we identified where a WTHD was expressed outside a context of suffering, we do not rule out the possibility that other similar cases may exist. Just as for some patients death was seen as release from their illness, the patient referred to above seems to have gained some relief from the knowledge that her illness was progressing, and that death was imminent.

The second theme, reasons, captures how a WTHD can represent a response to physical, psychological/emotional, and social factors in the context of intense suffering, and a perceived loss of self. Although physical pain was for many years considered the primary cause of the WTHD, studies conducted since the late 1990s offer a more complex view (26). Thus, while several authors report a close relationship between the WTHD and, for example, greater functional impairment, and dependency (27,28), there is evidence to suggest that psychological, and emotional factors play an important role in the emergence of such a wish (3,5,26). In terms of a person's subjective experience, it is not possible to separate physical symptoms, and functional impairment from the impact they have on the person's relationship to his or her surroundings, and the psychological or existential suffering that results. Indeed, physical pain, and loss of functionality are inextricably linked with all other aspects of the self, and as such they may, for example, lead to feelings of hopelessness and helplessness making it difficult for the patient with advanced disease to find meaning in life. This multifaceted suffering, which cannot be reduced to its constituent parts, exemplifies what Cicely Saunders (29) referred to as ‘total pain’. Some participants felt that were it not for their physical pain they would not wish to die. However, other statements made by patients indicate that the experience of pain cannot be understood in isolation from its impact on the person’s psychological and emotional state and their relationship with the immediate environment. These apparent contradictions may reflect how researchers have explored or assessed pain in this context, since instruments used in cross-sectional studies are unable to capture the full intensity and experiential impact, with qualitative research offering a more nuanced holistic account of the experience of pain.

In our synthesis psychological factors are prominent as triggers of the WTHD. Quantitative studies, assessing psychological factors related to the WTHD, could add valuable, complementary information to the findings of the qualitative studies. Depression, for example, has been widely reported as a mediating factor for the WTHD (30,31). In a study by Breitbart et al. (30) it was observed that patients who presented the desire to die were four times more likely to be depressed than those who did not. In another study, Akechi et al. (31) showed that, of a sample of 1721 patients, 220 were diagnosed with major depression and that 51.4% of these had suicidal ideation.

In this synthesis, only three of the 14 included studies (2,23,24) directly referred to the need to address depression. However, in the light of our analysis of study data, clear symptoms of depression can be detected: loss of interest or pleasure in usual activities, loss of energy, feelings of worthlessness, self-reproach, fearfulness, pessimism, recurrent thoughts of death (32).

Similarly, it is important to explore and evaluate hopelessness, helplessness, purposelessness, etc., recurrent states for those who experience the WTHD, as demonstrated by the majority of the participants in our analysis.

Another factor linked to the emergence of the WTHD is demoralization syndrome which can be clinically differentiated from depression and is a powerful mediator of the WTHD in these patients (33,34). Three studies included in this synthesis refer to demoralization (2,4,9). The fact that participants presented hopelessness, loss of meaning and purpose, sense of helplessness, social isolation and lack of support among other findings (35) could be symptomatic of demoralization syndrome, at least in some of the sample. This finding is especially relevant for clinicians, who could implement measures for its detection and treatment (36).

Another aspect that was prominent in our synthesis was that many patients referred to the fear of future physical symptoms or future suffering rather than actual current physical symptoms. Our analysis identified that many patients had already experienced episodes of acute poor symptom control with past experience leading them to be fearful when anticipating the future process. In this way, we can further confirm an overlap between physical or psychological factors. Furthermore, we can see how the symptom picture offers a basis for the psychological response to the situation being encountered: in this case, through fear.

While the authors of the included studies identify diverse reasons for the WTHD, these are, in fact, inter-related. In some cases it is difficult to differentiate the physical, psychological, emotional, social, and existential dimensions of patients' experience. Thus, for example, although aspects such as meaning in life or loss of the sense of dignity are often described as psychological/emotional/existential issues, in our analysis they relate to the sub-theme of *loss of self*, in other words, a loss of identity that covers all dimensions of personhood.

The concept of dignity in the context of patients with advanced illnesses is crucial because it resolves the inevitable difficulty in trying to delineate physical from psychological suffering. It allows us to understand that patients perceive suffering and simultaneously attribute meaning to their experience. Dignity has been defined as an intrinsic and absolute quality of human beings, which can be perceived as a sense of identity, in relations to physical, psychological, spiritual and social factors mediated by illness (37). The perception of personal dignity, understood as how a person perceives themselves in the light of suffering, the loss of functionality, changes in physical image etc., along with the emotional impact of experiencing illness, holds special relevance. In this sense, dignity encompasses very different aspects from loss of the sense of dignity mediated by the loss of functionality (loss of bodily function, cognitive impairment, loss of value of life, loss of quality of life) through to dignity understood as personal identity (loss of self-worth, loss of image, loss of self-esteem, loss of social identity: fear of being vulnerable, shame) (37–41).

The third theme that emerged from our synthesis was *meanings*. Identifying the meanings the WTHD may hold (other than simply a desire to die) is crucial for understanding the complex and dynamic nature of this phenomenon. Some studies point out how the WTHD can fluctuate over time (42,43), such that an individual may experience contradictory wishes (7,10,24). Such cases highlight the need for caution when exploring the meanings that a given individual may attribute to the expression of a WTHD. Furthermore, although the meanings identified in this updated review were derived from the statements made by participants, the meaning of a WTHD may also be influenced by the values and moral understanding of patients (10,44). In this respect, it is important to explore the cultural and personal background of a patient who expresses a WTHD so as to be able to properly contextualise what is being expressed.

The fourth theme, functions, considers the WTHD as a means of communicating and as a form of control. All the studies revealed that the WTHD served to express more than just a desire to die. The communicative function of the WTHD was clear in some cases, in strengthening family ties and highlighting how important the care and presence of loved ones was to the patient. In some way, the WTHD is also experienced as a way of reducing the burden on family members and of saving them from experiencing a protracted process before death (4,23). Involving relatives in decision-making meant that responsibilities were shared and helped ensure, to some extent, that the patient would not be abandoned to their fate. Occasionally, the expression of a WTHD was used to make relatives, friends or professionals feel that they should do more for the patient, or to obtain personal gain. In the majority of cases, however, the expression of a WTHD was a way of communicating the extent of suffering (24).

The WTHD as a form of control featured in our previous meta-ethnography. For this update, however, our analysis paid closer attention to the legal context, especially in countries in which euthanasia or AS has been decriminalised. Of the 14 studies, six (4,8–11,23) refer explicitly to physicians or organisations that could provide support to persons interested in euthanasia or AS. Making contact with right-to-die organisations was seen as the final act of control available to someone with a terminal illness. Some patients who expressed this desire for control ended up dying through the administration of lethal drugs (9,23). In countries where such practices remain illegal, patients alluded to hypothetical plans in which the possibility of suicide was contemplated. Such plans appeared to generate a sense of control and of relief among patients (without the irreversibility associated with euthanasia or AS). Once again, the primary motive for such control was the wish to put an end to suffering. In sum, the existence of legislation that permits euthanasia or AS can influence decision-making for advanced patients at the end of life (4).

The final theme, *lived experience of a timeline toward dying and death*, contextualises patients' statements within a temporal framework. The experience of time only appeared explicitly (i.e. as a theme identified in the data analysis) in one study (21). However, when patients in other studies spoke of their experience of progressive deterioration, fear, anguish, hopelessness, and loss of control, etc. they made implicit reference to their life past, present, and future. This temporal aspect of the WTHD, captured not only in qualitative studies (45), highlights the importance of a more detailed exploration of patients' experience when seeking to address their doubts, and concerns.

Strengths and limitations

This updated review and synthesis of the published literature on the WTHD has brought a more detailed understanding of the phenomenon. For the present qualitative analysis, two researchers (ARP and ABo) joined two authors from the previous meta-ethnography (CMR, ABa), and this triangulation of researchers (46) injected a fresh perspective. Inclusion of studies from countries beyond those from the earlier meta-ethnography (specifically, Germany, The Netherlands, Switzerland, and Thailand) increases the transferability of results. So far, we have been unable to identify published studies of the WTHD in Africa, South America, and the Middle East. As in our previous review, we achieved data saturation in the present study. Only one new theme ('lived experience of a timeline towards dying and death') was identified, a theme already implicit in the earlier meta-ethnography. Other themes that emerged encapsulated previously identified themes, which were here reclassified, and reconceptualised.

One limitation of the present study concerns the difficulty of synthesising findings from primary qualitative studies. Not all studies used the same conceptualisation of the WTHD, and the research objectives of some studies only touched indirectly upon the phenomenon. Likewise, not having access to the original interviews limits the available data.

Implications for practice and future research

The WTHD is a complex phenomenon to which various reasons, meanings, and functions may be attributed. This highlights the need for professionals to be trained so that they can respond to and understand the impact of a life-threatening illness on the individual. Furthermore, an understanding of the factors that can trigger a WTHD may help to prevent its emergence. From a quantitative perspective, many studies have linked the emergence of the WTHD with the aforementioned factors. Some of these even analyse predictors of the WTHD (28,33,47,48). For example, Rodin et al. (49) used a structural equation model to support the view that depression, hopelessness, and the desire for hastened death represent final common pathways of distress determined by multiple risk and protective factors. Vehling et al. (48), using a similar methodology, showed that loss of dignity partially explains the positive association between the number of physical problems and demoralization in cancer patients. Robinson et al. (33) suggest that depressive symptoms, loss of meaning and purpose, loss of control, and low self-worth are relevant psychological mechanisms that probably contribute to the development of a desire to hasten death in palliative care patients. Recently, Guerrero-Torrelles et al. (50) show a model whereby meaning in life (specifically in the sense of diminished meaning) and, to a lesser extent, depression have a mediator effect on the relationship between physical impairment and the WTHD in patients with advanced cancer. Nevertheless, the large majority of quantitative studies have cross-sectional designs, which limits the possibility of establishing causality, as well as only studying variables that could be quantified. In this sense, qualitative studies offer a more in-depth study of the phenomenon as a whole.

It has recently been suggested (28) that proactively asking patients about a potential WTHD could be beneficial. Further studies are required to explore this strategy. Given that social factors contribute to the emergence of a WTHD, future research should explore how the expression of a WTHD is experienced by the person's relatives, and what meanings it may have for them. Systematic guidelines regarding the WTHD are needed to help health care professionals respond adequately to the needs of these patients.

CONCLUSIONS

The WTHD in patients with advanced disease cannot be understood outside the context of their suffering, a prerequisite for its emergence in this population. However, every expression of a WTHD will have associated reasons (the whys) and functions (for what purpose), and its meaning may vary by cultural background and lived experience, to not necessarily be synonymous with a genuine desire to die. In countries where EAS have been decriminalised, the expression of a WTHD may be seen as a way to end suffering. All these aspects underline the need to explore the reasons, meanings, and functions that a person attributes to such a wish, as only by doing so will we be able to understand his or her experience and develop appropriate individualised care plans.

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Contributions

Contributors CMR and ABa designed the study. CMR collected data. ARP and CMR conducted data analysis. ARP, CMR and ABa wrote the manuscript. ABa and ABo made substantial contributions to the identification of relevant literature, the interpretation of findings and were involved in drafting the manuscript and revising it critically. All authors gave final approval to this manuscript.

Competing interest

The authors declare no conflict of interest.

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Data sharing statement

All data supporting this study are provided as supplementary information accompanying this paper. Further information can be obtained from the corresponding author.

REFERENCES

1. Lavery J V., 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(9279):362–7. 2.
2. Kelly, B., Burnett P, Pelusi D, Badger S, Varghese F, Robertson M. Terminally ill cancer patients' wish to hasten death. Palliat Med 2002;16:339–45.
3. Hudson P, Krstjanson L, Ashby M, Kelly B, Schofield P, Hudson R, 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(7):693–701.

4. Ohnsorge K, Gudat H, Rehmann-Sutter C. What a wish to die can mean: reasons, meanings and functions of wishes to die, reported from 30 qualitative case studies of terminally ill cancer patients in palliative care. BMC Palliat Care 2014;13(38).

5. Monforte-Royo C, Villavicencio-Chávez C, Tomás-Sábado J, Mahtani-Chugani V, Balaguer A. What lies behind the wish to hasten death? A systematic review and meta-ethnography from the perspective of patients. PLoS One 2012;7(5):e37117.

6. 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(2):165–71.

7. Mak YYW, Elwyn G. Voices of the terminally ill: uncovering the meaning of desire for euthanasia. Palliat Med 2005;19(1):343–50.

8. Schroepfer TA. Mind Frames Towards Dying and Factors Motivating Their Adoption by Terminally Ill Elders. J Gerontol 2006;61(3):129–40.

9. Dees MK, Vernooij-Dassen MJ, Dekkers WJ, Vissers KC, van Weel C. “Unbearable suffering”: a qualitative study on the perspectives of patients who request assistance in dying. J Med Ethics 2011;37(12):727–34.

10. Ohnsorge K, Keller H, Widdershoven G, Rehmann-Sutter C. Ambivalence’at the end of life How to understand patients’ wishes ethically. Nurs Ethics 2012;19(5):629–41.

11. Ohnsorge K, Gudat H, Rehman-Sutter C. Intentions in wishes to die: analysis and a typology – A report of 30 qualitative case studies of terminally ill cancer patients in palliative care. Psycho-Oncology 2014.

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

13. Lang H, France E, Williams B, Humphris G, Wells M. The psychological experience of living with head and neck cancer: A systematic review and meta-synthesis. Psycho-Oncolog 2013: 2648–63.

14. France EF, Ring N, Noyes J, Maxwell M, Jepson R, Duncan E, et al. Protocol-developing meta-ethnography reporting guidelines (eMERGe). BMC Med Res Methodol 2015;15:103.

15. France EF, Wells M, Lang H, Williams B. Why, when and how to update a meta-ethnography qualitative synthesis. Syst Rev 2016;5(1):1.

16. Wong SSL, Wilczynski NL, Haynes RB. Developing optimal search strategies for detecting clinically relevant qualitative studies in MEDLINE. Stud Health Technol Inform 2004;107:311–4.

17. Wilczynski NL, Marks S, Haynes RB. Search strategies for identifying qualitative studies in CINAHL. Qual Health Res 2007;17(5):705–10.

18. McKibbon KA, Wilczynski NL, Haynes RB. Developing optimal search strategies for retrieving qualitative studies in PsycINFO. Eval Health Prof 2006;29(4):440–54.

19. CASP. Critical Appraisal Skills Programme. Ten questions to help youmake sense of qualitative research. Oxford; 2013.

20. Stiel S, Pestinger M, Moser A, Widdershoven G, Lüke U, Meyer G, et al. The Use of Grounded Theory in Palliative Care: Methodological Challenges and Strategies. Palliat Med 2010;13(8):997–1003.

21. Pestinger M, Stiel S, Elsner F, Widdershoven G, Voltz R, Nauck F, et al. The desire to hasten death: Using Grounded Theory for a better understanding "When perception of time tends to be a slippery slope." Palliat Med 2015;29(8):711–9.

22. Nilmanat K, Promnoi C, Phungrassami T, Chailungka P, Tulathamkit K, Noo-urai P, et al. Moving Beyond Suffering: the Experiences of Thai Persons With Advanced Cancer. Cancer Nurs 2015;38(3):224–31.

23. Pearlman RA, Hsu C, Starks H, Back AL, Gordon JR, Bharucha AJ, et al. Motivations for physician-assisted suicide. J Gen Intern Med 2005;20(3):234–9.

24. Coyle N, Sculco L. Expressed desire for hastened death in seven patients living with advanced cancer: a phenomenologic inquiry. Oncol Nurs Forum 2004;31(4):699–709.

25. Balaguer A, Monforte-Royo C, Porta-Sales J, Alonso-Babarro A, Altisent R, Aradilla-Herrero A, et al. An international consensus definition of the wish to hasten death and its related factors. PLoS One 2016;11(1):1–14.

26. Monforte-Royo C, Villavicencio-Chávez C, Tomás-Sábado J, Balaguer A. The wish to hasten death: a review of clinical studies. Psycho-Oncology 2011;20(8):795–804.

27. Rodin G, Zimmermann C, Rydall A, Jones J, Shepherd FA, Moore M, et al. The desire for hastened death in patients with metastatic cancer. J Pain Symptom Manage 2007;33(6):661–75.

28. Villavicencio-Chávez C, Monforte-Royo C, Tomás-Sábado J, Maier MA, Porta-Sales J, Balaguer A. Physical and psychological factors and the wish to hasten death in advanced cancer patients. Psycho-Oncology 2014;23:1125–32.

29. Saunders C. The last stages of life. Am J Nurs 1965;65(3):70–5. 30.

30. Breitbart W, Rosenfeld B, Pessin H, Kaim M, Funesti-Esch J, Galietta M, et al. Depression, Hopelessness, and Desire for Hastened Death in Terminally Ill Patients With Cancer. J Am Med Assoc 2000;284(22):2907–11.

31. 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(2):141–5.

32. Endicott J. Measurement of depression in patients with cancer. Cancer 1984;53(10 Suppl):2243–9. 33.

33. Robinson S, Kissane DW, Brooker J, Hempton C, Burney S. The Relationship Between Poor Quality of Life and Desire to Hasten Death: A Multiple Mediation Model Examining the Contributions of Depression, Demoralization, Loss of Control, and Low Self-worth. J Pain Syptom Manag 2017;53(2):243–9.

34. Kissane DW, Wein S, Love A, Lee X, Kee P. The demoralization scale: a report of its development and preliminary validation. J Palliat Care 2004;20(4):269–76.

35. Kissane DW, Clarke DM, Street AF. Demoralization syndrome--a relevant psychiatric diagnosis for palliative care. J Palliat Care 2001;17(1):12–21. 36.

36. Robinson S, Kissane D., Brooker J, Burney S. A systematic review of the demoralization síndrome in individuals with progressive disease and cancer: A decade of research. J Pain Symptom Manage 2015;49(3):595–610.

37. Rodríguez-Prat A, Monforte-Royo C, Porta-Sales J, Escribano X, Balaguer A. Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography. PLoS One 2016;11(3):e0151435.

38. Street AF, Kissane DW. Constructions of dignity in end-of-life care. J Palliat Care 2001;17(2):93–101.

39. Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: A developing empirical model. Soc Sci Med 2002;54(3):433–43.

40. Enes SPD. An exploration of dignity in palliative care. Palliat Med 2003;17(3):263–9.

41. Guo Q, Jacelon CS. An integrative review of dignity in end-of-life care. Palliat Med 2014 31;28(7):931–40.

42. Chochinov HM, Tataryn D, Clinch JJ, Dudgeon D. Will to live in the terminally ill. Lancet 1999;354(9181):816–9.

43. Galushko M, Strupp J, Walisko-Waniek J, Hahn M, Löffert S, Ernstmann N, et al. Validation of the German version of the Schedule of Attitudes Toward Hastened Death (SAHD-D) with patients in palliative care. Palliat Support Care 2015;713–23.

44. Rehman-Sutter C. End-of-life ethics from the perspectives of patients' wishes. In: Rehman-Sutter C, Gudat H, Ohnsorge K, editors. The Patient's Wish to Die Research, Ethics, and Palliative Care. 1st ed. Oxford: Oxford University press; 2015.

45. Chochinov HM, Wilson KG, M E, N M. Desire for death in the terminally ill. Am J Psychiatry 1995;152:1185–91.

46. Mays N, Pope C. Qualitative Research: Rigour and qualitative research. BMJ 1995;311:109–12.

47. 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(1):75–81.

48. Vehling S, Mehnert A. Symptom burden, loss of dignity, and demoralization in patients with cancer: a mediation model. Psycho-Oncology 2014;23(3):283–90.

49. Rodin G, Lo C, Mikulincer M, Donner A, Gagliese L, Zimmermann C. Pathways to distress: The multiple determinants of depression, hopelessness, and the desire for hastened death in metastatic cancer patients. Soc Sci Med 2009;68(3):562–9.

50. Guerrero-Torrelles M, Monforte-Royo C, Tomás-Sábado J, Marimon F, Porta-Sales J, Balaguer A. Meaning in life as a mediator between physical impairment and the wish to hasten death in patients with advanced cancer. Submitted

SUPPLEMENTARY FILES

Table-S1. Final database search strategy

1	desire to hasten death
2	wish to hasten death
3	euthanasia [Mesh]
4	suicide, assisted [Mesh]
5	end of life decisions
6	wish to die
7	1 or 2 or 3 or 4 or 5 or 6
9	palliative care
10	end of life care
11	end of life
12	9 or 10
13	chronic disease
14	chronic illness
15	advanced disease
16	advanced illness
17	advanced cancer
18	life limiting illness
19	terminally ill
20	life threatening illness
21	life threatening condition
22	13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21
23	Qualitative Pubmed or CINAHL filter
25	7 and 12 and 22
26	25 and 23
27	26 not (child*) or (pediatr*)

Table-S2. Methodological quality of included studies, assessed using CASP criteria: qualitative research checklist

Reporting Criteria (CASP)	**N (n=14)**	**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	14	(1–14)
– Why it is important	14	(1–14)
– Its relevance	14	(1–14)
2) Is a qualitative methodology appropriate? **Consider:** – If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants	14	(1–14)
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	12	(1,3–10,13,14)

use?)		
4) Was the recruitment strategy appropriate to the aims of the research? Consider: -If the researcher has explained how the participants were selected	13	(1–10,12–14)
– If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study	13	(1–10,12–14)
– If there are any discussions around recruitment (e.g. why some people chose not to take part)	11	(1–9,12,14)
5) Were the data collected in a way that addressed the research issue? Consider: - If the setting for data collection was justified	14	(1–14)
– If it is clear how data were collected (e.g. focus group, semi-structured interview, etc.)	13	(1–9,11–14)
– If the researcher has justified the methods chosen	7	(4,6,7,9,10,13,14)
– If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they use a topic guide?)	11	(1,3,4,6–9,11–14)
– If methods were modified during the study. If so, has the researcher explained how and why?	2	(10,14)
– If the form of data is clear (e.g. tape recordings, video material, notes, etc.)	14	(1–14)
– If the researcher has discussed saturation of data.	10	(1,2,5–7,9,10,12–14)
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	(4,7)
formulation of research questions	3	(1,3,7)
data collection, including sample recruitment and choice of location	5	(1,3,4,6,7)
- 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	13	(1–5,7–14)
– 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	14	(1–14)
8) Was the data analysis sufficiently rigorous? Consider: – If there is an in-depth description of the analysis process	12	(3–14)
– If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?	12	(1,3–5,7–12,14)
– Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process	6	(1,3,4,9,10,14)
– If sufficient data are presented to support the findings	12	(1–8,10,12–14)
– To what extent contradictory data are taken into account	1	(11)
– 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	14	(1–14)
– If there is adequate discussion of the evidence both for and against the researcher's arguments	9	(1,3,6,7,9,11–14)
– If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)	10	(1,3,6–9,11–14)
– If the findings are discussed in relation to the original research questions	14	(1–14)
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?)	13	(1–9,11–14)
– If they identify new areas where research is necessary	13	(1–9,11–14)
– 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	8	(1,3,5–9,11)

Table-S3. The seven stages of meta-ethnography, summarising what each step entailed in the previous and the present review

Noblit and Hare's 7 steps (15)	**What each step entailed in our original meta-ethnography** (16)	**What each step entailed in the present, updated meta-ethnography**
1. "Getting started" (the topic focus)	To analyse the meaning of and motivation for the WTHD in patients with chronic illness or advanced disease.	To analyse the WTHD in patients with chronic illness, advanced disease or life-threatening illness.
2. Deciding what is relevant to the initial interest	Design a search strategy to identify qualitative studies (December 2000-November 2009).	Design of a revised optimal search strategy. For inclusion: qualitative studies (December 2000-January 2016). Studies from original meta-ethnography and from update to be integrated.
3. Reading the studies	Generate list of key concepts to identify common and disparate concepts and themes, both within and across studies. Findings from the research reports divided into text units coded by words, sentences or paragraphs, according to content. Codes grouped into themes to define characteristics or different dimensions of the phenomenon studied.	Generate list of key metaphors using Atlas.ti software to identify common and disparate concepts and themes, within and across studies. No distinction to be made during reading and analysis between previously reviewed and new studies. Findings from research reports to be handled in same way as for the original meta-ethnography.
4. Determining how studies are related	Directly compare concepts from primary studies using reciprocal translations (generating metaphors to express similarities between study findings).	Directly compare concepts from primary studies using reciprocal translations (as for the original meta-ethnography).

5. Translating the studies into one another	Having identified main concepts from each study, search for their presence or absence in all the studies. Comparison to begin with themes identified in the earliest published article and to proceed in chronological order of publication. Translate themes to the whole sample and to each individual study.	Having identified concepts from each study, search for the presence or absence of main concepts in all studies. Comparison again to follow chronological order. Translate themes to the whole sample and to each individual study. During the analysis, return to the original themes, comparing them with the new themes that emerge. Themes emerging from the update can confirm or broaden the original themes, or constitute new themes.
6. Synthesising translations	Bring together translated concepts within a synthesis, starting from identified themes, and match them with their respective quotations, resulting in themes within final synthesis. Finally, derive explanatory model.	Bring together expanded number of translated concepts within an expanded final synthesis. Concepts can confirm original translated concepts, but might also lead to new explanatory model.
7. Expressing the synthesis	Express synthesis as themes with an accompanying narrative in a scientific journal.	Again, express synthesis as themes with an accompanying narrative for submission to a scientific journal.

Table-S4. Comparison of yield between Original Review and Updated Review

Noblit and Hare's 7 steps (15)	**Original Review**	**Updated Review**
1. "Getting started" (the topic focus)	7 studies (December 2000-November 2009)	14 studies: 7 original + 7 new studies (December 2000-January 2016)
2. Deciding what is relevant to the initial interest		
3. Reading the studies		
4. Determining how studies are related	10 translated concepts	25 translated concepts
5. Translating the studies into one another		
6. Synthesising translations	6 themes	5 themes
7. Expressing the synthesis	Explanatory model	New explanatory model

Table-S5. Classification of verbatim statements from the studies by theme and sub-theme

Themes, subthemes and quotations	**Some of the related themes**
1. Reasons for the WTHD	
1.1 Physical factors	
"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 [sic] 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" (1).	Dependency Progressive deterioration Loss of function Loss of the self Loss of the sense of dignity
"… If I'm going to be rolling around in my own faeces because I have no control, then forget it" (1).	Loss of function Loss of control
"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, they're 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 in pain and agony and people coming in, people being upset, them being upset" (1).	Loss of function Anticipation of future suffering Not wanting to make others suffer
"I can't move, just lie here... feeling like a vegetable… a useless person... needing people to feed me" (4).	Loss of function Loss of independence Dependency Loss of value
"But really yes, to see a man, who only exists of pain, who maybe is cognitively impaired and isn't able to participate actively in life, this man, who only lies in bed, not noticing his surroundings…" (14).	Suffering Loss of physical function and cognitive impairment Loss of daily life activities Loss of value
"I say: I have made my decision. I don't want you to treat me any longer. Someone says, now you are probably too weak for chemo. I say: if I'm not too weak and they want to give me chemo, I will refuse it, because in the little time that is left to me I want quality of life, not quantity of life. I decided that a year ago: if this were to overcome me, then that's what I would choose" (9).	Loss of quality of life Desire for control over life
"If you get cancer, you'll get pain. Cancer is a painful disease. It'll just get more and more painful" (4).	Progressive deterioration Suffering Lived experience of time Anticipation of future suffering
"Whether it gets better or not, it's destined. I'll wait to die. There's no way out even if the pain returns. It'll come when it may. I'll just go along with the pain and die. Nothing would help" (4).	Pain Suffering Hopelessness WTHD as unbearable situation with no

	other way out
“The side effects of the treatment are unacceptable… the Prednisone destroys you. For example, it destroys your muscles. My thighs are so weak I can’t get up from the floor, and I don’t have the energy to exercise. The whole thing is a vicious circle… My face… looks like a melon… I look like a frog in heat” (5).	Progressive deterioration Loss of function Loss of image: shame
“... 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” (5).	Progressive deterioration Lived experience of time (there is no future) Hopelessness Losses
“The pain could happen immediately or it could happen an hour or two later. And then I have to see about seeing [my provider] again. It is a treadmill that I'm on; I can't get off of it, and I've had it. And I can't live this anymore” (5).	Anticipation of future suffering Unbearable suffering with no other way out
“Well, the pain that I had before with the rheumatoid arthritis I knew that I could handle—... But this pain that I have, I’m not sure—I can’t get rid of it with the pain medicine always... To give me enough to keep that pain under control, they’d have to put me out, and I don’t want my son to have to take care of a bed patient” (5).	Not wanting to be a burden Unbearable suffering with no other way out
“I have fecal incontinence. I can no longer swallow and in hot weather I really envy people who can drink” (9).	Loss of physical functions Loss of control Loss of the sense of dignity: shame
“The way to my bed is endless and finally I get there. It takes a lot of energy, but once I’m in bed, it takes an hour just to gather my strength again” (9).	Loss of function Progressive deterioration Losses
“I am in pain all the time, I am in pain at night, I wake up with pain and I go to bed with pain. If they could take away half my pain I wouldn’t be thinking about euthanasia” (9).	Pain Suffering Will to live but not in this way Hastened death as a way of ending suffering
“I was simply nauseous and my energy was just running out. And I said that I wished that, just for a short period of time, I could eat normally and not have to fight to keep it down and that I wanted to have a little more energy. Then I stopped the chemo and indeed I had that improvement” (9).	Consequences of the medical treatment
“Yes, I could not tell it, because I have just no pain now. That’s maybe less [the idea that her illness should proceed faster]. If I had pain now or so, then I would say: immediately. But then… I will have to wait. That’s not my business. That’s God’s business” (11).	Pain as *mediator* of the WTHD Ambivalence Wish to live but not in this way
P: “It’s horrible, I can tell you. It’s horrible. […] the whole situation. I: The situation. Not being able to get out of it. P: Not being able to get out of it, and every morning the same thing: waking up, being washed, lying there till the evening, the same pain” (12).	Dependency Suffering WTHD: unbearable situation with no way out (other than death) Despair

“I sit back and I say, ‘since I’m already dying, and since I’m already gone, lost my energy. Why? Why do I also have to take these disgusting pills?’ and it seems that every day there’s something more, something more disgusting” (7).	Hopelessness Tired of fighting
1.2 Psychological factors	
“... 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 realise that this is virtually the end of it all. There’s no future really. You can’t plan anything” (17).	Hopelessness Progressive deterioration Limitation of activities Loss of function Lived experience of time
“Sometimes I start yelling at my shrink that this is horrible, that why don't I die right now?...Why do I have to live through this?” (3)	Fear of the dying process Unbearable suffering Loss of meaning
“I don’t want to undergo that [expletive] feeling of helplessness, that there’s not a [expletive] thing that I or anyone else can do” (3).	Helplessness Hopelessness
“I just don’t want to be in so much suffering... to endure these psychological effects” (4).	Suffering
“Not much hope, nor would there be any miracles… You doctors can’t help when the patients deteriorate and then drop dead…” (4).	Progressive deterioration Hopelessness
“Someone with a tube sticking up the bottom, a tube sticking into the nostrils, another somewhere else. I mean, what for? Can you save them?” (4).	Hopelessness Loss of meaning
“I asked the doctor, ‘Doctor, do people with cancer get a lot of pain?’ He answered, ‘In the majority they do.’ Then I asked, ‘Is it possible not to be like that?’ He answered, ‘Possible, I suppose.’ Ah…” (4).	Fear of suffering
“Some don't have loved ones around. They have nobody to care for them. Others have relatives but they don't care… I only have one daughter. If she doesn't help, who is going to help?… So miserable that I cannot express in words” (4).	Hopelessness Fear about the future Lack of social support
“My first husband, he suffered a long time. He had on those machines, and I used to say, ‘God,’ I said, ‘don’t let me go under those machines” (6)	Fear of suffering
“I never thought about giving up but my fear was that I didn’t know much about cancer. There are so many people that linger, and I was afraid that I could not cope. I know I will die, but I don’t want to be lingering and suffering and people around me to suffer with me. So I thought, ‘I will go for a swim’ and I don’t know how to swim or I would go to a place like Holland. I just don’t want to be lingering, like people that can hardly talk and are really suffering and I don’t want to do that. It’s the only thing that makes me feel a little bit emotional. I don’t want to deal with it so I think I would speed up things myself. I don’t want to be lingering here in palliative care, lying day and day, slowly dying. Oh no, I don’t want to do that. So, suicide is a way of exiting. I don’t want to talk about that because I like life and I have lots to live for, but if I come to the point when I am too weak to do anything, then I don’t want to stay” (7).	Anticipation of future suffering Progressive deterioration Not wanting to be a burden WTHD as a way of ending suffering WTHD so as to spare others from burden Having a plan Will to live but not in this way
“It is such an aggressive form of cancer. I saw all my energy going down the drain- what I could still do last week I can’t do at all now. I really enjoyed my life, but now I have just to wait and see how things go and what death will look like” (9).	Hopelessness Suffering Will to live but not in this way

1.3 Social factors	
“I think it's very important for every single person to feel that they belong, and, and that they fit in a community, in a city, in a country, in a world, ah, in nature. The, the ah, and I think when we no longer feel that you have these linkages, and that the linkages are valued for everything that you're connected with, whether it, you know, family or friends or, you know, associates, or whatever, and your community, and city and all the rest of. Once the once, once you perceive that, that your relationships, all the links with, with other living things have deteriorated, and then, and they're not valued, then you've lost face. Dignity, then, has for me, has an awful lot to do with face” (1).	Loss of community Loss of the sense of dignity Disintegration Loss of value
“No matter how much they love you, you are always a burden. You automatically become a burden to everyone. Even to your own missus” (17).	Being a burden
“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” (3).	Not wanting to be a burden Fear of losing one’s own value/dignity in the eyes of others Loss of the self
“For them to see me in pain is suffering. To see family rushing around is so suffering… That makes me suffer. They spend a lot of money… I fear the rushing around would make her [wife] ill, burdening her” (4).	Suffering Not wanting to make others suffer
“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” (4).	Anticipation of future suffering Progressive deterioration Not wanting to be a burden
“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 48 hours 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 you just shivering, with no solution, is really hard” (7).	Pain (affects everything) Hastened death as a way of ending suffering Suffering as something worse than death Wish to live but not in this way Anticipation of future suffering
“ …that others are not affected by watching someone else wasting away for 2 month, willing to die and willing to die, but he does not. That is difficult for the family members” (10).	Not wanting to make others suffer
“I want to present myself as being as normal as possible, but everybody notices it: I stumble and I am slow and that is just not me because I always was a nimble girl” (9).	Loss of functions Fear of losing one’s own value/dignity in the eyes of others
“I am burdened myself, I am such a burden to others; I want to end this” (12).	Hastened death as a way of ending suffering Not wanting to be a burden
“I am not used to somebody helping me. This I feel is tantalizing, this is no life” (14).	Dependency Loss of control Loss of value of life

"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" (14).	Loss of the sense of dignity Loss of the self Fear of losing one's own value/dignity in the eyes of others Loss of image: shame Anticipation of cognitive impairment
1.4 Self - Identity - Losses	
"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" (5)	Loss of quality of life Loss of independency Loss of the self Loss of daily life activities
"I think passively sitting in my own garden, sitting on my own deck, would still be preferable to, to, to death. Quality of life, the concept of quality of life is shifted. I can live with an inactive life... and I'd still fight a bit to gain incrementally" (3).	Loss of function Loss of quality of life Ambivalence: wish to live and wish to die
"Finally the illness that dominates everything will wipe out all life has to offer me, what I feared most is exactly what will happen to me. I won't belong anymore, the emptiness of existence, the lack of independence, being unable to do things myself, being at the mercy of others whom I will have to beg to do the things I need in a way that's suitable for me" (9).	Losing Anticipation of future suffering Loss of control Loss of independence Loss of meaning in life Loss of daily life activities
"I just can't do what I used to. Um, I can't go out, I can't go to the store… I can't write a check for nothing. I, it's just a lot of things… Oh, I hate it" (6).	Limitation of activities Loss of function WTHD maintaining meaningful activities
"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" (6).	Loss of value Loss of will to live Helplessness
"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" (7)	Hopelessness Despair Loss of meaning in life Loss of will to live
"When I'm in pain, it is not so much the pain, it's the loss of control and the helplessness" (7).	Desire for control over life Helplessness
"The energy that I have always had, the positive (energy), that has made me as a person… but exactly this is getting less and less at the moment" (7).	Progressive deterioration Loss of the self

"The past few days even the news doesn't interest me anymore, I have less interest in the outside world. My brain no longer works and to me that is a part of human dignity and of unbearable suffering. I want to function normally and if I can't do that" (9).	Progressive deterioration Hopelessness Loss of the sense of dignity Loss of will to live Hastened death as a way of ending suffering
"I have become so weak because of the pain. I can't walk anymore, I can't eat anymore. My children have suffered enough. I don't want them to go through this again. Everybody has to lose their parents someday anyway" (9).	Pain Progressive deterioration Loss of self Not wanting to make others suffer
"…claustrophobia of my existence. To put it simply, it is insight without perspective. Never in my life have I felt any love. If there had been some warmth and love and safety, I could have grown" (9).	Loss of meaning in life Loss of will to live
"I can't drive anymore. I loved to paint and draw, but I can't do that either anymore. Everything I enjoyed is gone. And then, my sight became worse" (9).	Hopelessness Loss of meaning Limitation of activities Loss of function
"I'm not interested at all anymore, I just lie here and what's the point? There isn't any. I no longer read. Not books, not newspapers. I have CDs and the Walkman right here. Well, I've listened to, um, two CDs and that's enough. And yet I really loved music, but it's all over. I'm just not interested anymore…" (9).	Hopelessness Loss of will to live WTHD maintaining meaningful activities
"I lost my dignity, lying in bed in diapers, I am no longer the independent person I used to be" (9).	Loss of function Loss of independence Loss of the sense of dignity Loss of self
"And I don't feel this is a life for me [pause], carrying on living like this. That's why [pause] um, I am [pause] very – how should I put it, so you understand me – I'm on the road, on the move a lot and [pause] then I thought, if I can't live like before, life has no value, does it? And [pause] I drove my car a lot, and I can't do that anymore either. […] Yes, did a lot of travelling. […] I feel my life isn't worth anything at all any more, if I just lie here and wait" (12).	Loss of activities (that make life enjoyable) Loss of value Loss of will to live Loss of life's worth WTHD maintaining meaningful activities
"Activities with friends not possible—and indeed activities outside or with the family, I would say, meanwhile completely passed away" (14).	Limitation of activities
"You've become a bag of potatoes to be moved from 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" (1).	Loss of control Loss of the sense of dignity Loss of self-worth Loss of will to live

"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... Dignity is that I have control over my body, when, when, not, 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" (1).	Loss of control Loss of the sense of dignity Loss of self-worth Loss of will to live WTHD as a way of self-preservation
2. Suffering	
"To have pain and also breathlessness, that would be really terrible and so much suffering. My breathing is suffering and this affects my appetite. So many kinds of suffering… The social situation is suffering..." (4).	Physical factors
"I've seen other patients yelling in pain and they were suffering... so intolerable... Just to hear them was very suffering... It must have been so unbearable to have to yell like that. If they could endure it, they wouldn't have yelled" (4).	Anticipation of a painful death Fear of suffering
"I just don't want to endure these psychological effects... So much suffering... I have had the pain for four years... So many psychological effects… How can I bear it?" (4).	Suffering Unbearable situation with no other way out
3. Meanings of the WTHD	
3.1 Cry for helping	
"Why do I have to go through this? Why can't I just die right now?" and, "When I pray, I use [sic] to feel the power of God on me... Now I sometimes feel as though I am talking to the air" (3).	Suffering Loss of meaning Hopelessness
"When I was in excruciating pain… sometimes, I wanted to grab a knife and stab myself, and cut it [pain/cancer] out. I felt angry…why I am suffering so? I did not know what to do or how to deal with it. I could not work, so my life was no longer worth living. Continuing to live would only bring more suffering… I could not look after myself. I made [Buddhist] merits in the morning, offered food to monks. I prayed every day. I prayed to have the day, during which I was no longer able to perform my daily activities, as my last day of life… I prayed to die so that my suffering could end. I did not want to be fed by my children and grandchildren. Just let me die" (8).	Pain Loss of independence (not being able to perform activities of daily life) Not wanting to be a burden Loss of life's worth Suffering as something worse than death WTHD: unbearable situation with no way out (other than death) Despair
"I suffer so much that I can't recall when life was lovely and happy. My life is hell. My life is inhuman. I have such deep pain inside" (9).	Despair Suffering Loss of life's worth Loss of meaning WTHD: unbearable situation with no way out (other than death)

"Then all the red lights started flashing for me, because it was in your head, wasn't it. Then I thought: No! No, just no. Now I've simply had enough. […] I've tortured myself enough; I don't want to torture myself anymore" (12).	Disintegration Unbearable situation with no way out other than death (end suffering) Loss of life's worth
3.2 Unbearable situation with no way out other than death (end suffering)	
"There were many times when I was in such pain and such misery. I said, let me go... Finished... no more of this torture" (3).	Hastened death as a way of ending suffering Suffering as something worse than death Despair Pain Suffering
"I feel, deep inside, I don't want to feel hurting [sic]… that I want to end this… I ask God why he don't take me, why I suffer so much" (3).	Suffering Hopelessness Loss of meaning
"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 a vehicle to just, just stop my life" (3).	Fear of suffering Loss of will to live
"I can't bear the dying process so I'll short circuit it by dying" (3).	Fear of the dying process
"If the pain gets worse, then I want to be dead" (3).	Anticipation of future suffering Suffering as something worse than death Despair
"If I had to go through [an acute episode of shortness of breath] again, I would throw myself in front of a subway train. I am not going through that again" (3).	Anticipation of future suffering Pain Desire for control over life Fear of the dying process Despair
"... it should be up to me to decide… when I've had enough suffering... One of my landmarks, if I'm at the point where all I can do is lie on a bed all day long, then to me that's probably not living anymore" (5).	Autonomy Desire for control over life
"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, I wouldn't. No, I'd rather die" (1).	Progressive deterioration Dependency Loss of the self Fear of losing one's own value/dignity in the eyes of others: shame
3.3 To spare others from the burden of oneself	
"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" (3).	Being a burden WTHD as a form of altruism

"All of a sudden, it dawned on me that there was no solution, and if there was no solution to my cancer, then why was I hanging around? I got thinking about death as a practical matter. Why hang around and cause a lot of people a lot of grief?" (3).	Not wanting to be a burden
"[T]here's no question about wanting to make provisions for a hastened death should conditions become so unbearable. I want to spare my family as much of that grief as I can… [My mother] died of cancer, and we were constantly frustrated by not being able to do anything for her… And just watched her waste away. And what a terrible way to go" (5).	Loss of control Fear of suffering Not wanting to be a burden Not wanting to make others suffer
"I hope everyone can accept it… Most important is that my family wouldn't be heartbroken. If there were no suffering. I would like to see them for longer" (4).	Fear of suffering Not wanting to make others suffer Wish to live but not in this way
"That is somehow a vicious circle. If my wife sees me having a hard time, she is suffering from that. And then, when I see my wife suffering in extreme, and then I am in a bad shape, because after all, it is my fault" (10).	Not wanting to be a burden
"When I know that my life has become a burden to my loved ones, I would rather die. I think of death as a way to release me from this frustration" (8).	WTHD as a way of ending suffering Not wanting to be a burden Suffering as something worse than death WTHD: unbearable situation with no way out (other than death) Despair
"I always pray that I can release people, eh, that I can free them of a burden, release the others also. That I do not always have to rely on help, I want… My whole life, I only worked and always took care of [others] myself… Then after this it's simply difficult, if you always have to have other people. That you have to be a burden…That I've never like" (11).	Not wanting to be a burden
"I would like to go. You see, I want to let people off the hook. I don't, I don't like it that they always have to… they all have a life too and I don't want to, that I… well" (12).	Not wanting to be a burden
"I can't just walk away like that. One time you think, 'I might as well give up.' But that's easy for me, but not easy for them [family]. There are other people [to consider]" (7).	Not wanting to be a burden
3.4 To preserve self-determination in the last moments of life	
"I immediately turned to the option of Exit [pause], because I said I'd like to have this option whatever happens. If things become unbearable for me for some reason, but I'm still not dying, then I'd like to be able to grant myself my own death. And I saw to everything, so that it's ready, that I have the prescription, and talked to those people. They're quasi on call now. […] This is really only about ending a situation that has become unbearable, and not having to rely on either being hit by another stroke or some doctor being understanding after all. I want to be able to keep this in my own hands for when the moment comes. I was a very self-determined person all my life, and that's very important to me" (12).	Anticipation of a painful death Desire for control over life Hastened death as a way of ending suffering Having a plan Suffering as something worse than death WTHD as a form of control

“I have no desire to commit suicide, but I have no desire to take it out of my hands either” (7).	Autonomy Desire for control over life Wish to live but not in this way
3.5 Will to live but not in this way	
“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” (3).	
“Wish to live but can’t live; wish to die but can’t die” (4).	Suffering
“It is torturous… thinking when I am going to die to escape from this suffering. But when I am not in pain, I want to live. When the symptoms disappear, I want to continue living, as I do not want to depart from my loved ones. Actually, I do not want to be parted [die]… when I do not experience any symptom. But when I suffer the symptoms, I again wish to die to escape the suffering” (8).	Pain as *mediator* of the WTHD Hastened death as a way of ending suffering
“No, not at this moment, but on those days when I am so miserably sick” (13).	Anticipation of future suffering and pain Having control
4. Functions of the WTHD	
4.1 WTHD as a means of communication	
“So I was glad that I could talk to him [husband] about it [WTHD]. Actually I was the only one, I was able to communicate that and [pause] just be able to let go of the thought, rather than letting it eat into you. Whether you then do it or not is actually secondary. It’s bad for people if they can’t say to anyone: you know, I have thoughts like this sometimes. So I really am glad that I was able to discuss it with him [husband], it did me good as well” (12).	Family reinforcement
“I shared that I wouldn’t do it until we discussed it together… She didn’t have to worry about me taking the pills… It wasn’t fair to them... It would leave them wondering, did they do, you know, contribute to it, did they do all they could... And I want them to feel comfortable that they’ve done everything” (3).	Manipulation
“I’ve also said these tongue-in-cheek things: so, now I’m starting to collect pills. Yes. And then the people concerned, the ones you say that to, they’re shocked, and yet it was said tongue-in-cheek. I: To test their reaction. P: Yes, perhaps sometimes a bit of deliberate provocation” (12).	Expression of the WTHD so as to observe people’s reaction
4.2 WTHD as a form of control - Having a plan – Just in case / avoiding suffering (future)	
“Exit would really just be there for an emergency, and not because that's what I'd wish. That would only be if I felt I couldn't get back off this track [...] If it gets that hard, and I don’t know how to put on my socks or I’m so dead sick that I think: for Heaven’s sake huuh… then I would wish for it to end, just to be relieved, just that it ends. […] Yes, it’s rather just being set free from this state” (12).	Anticipation of future suffering Desire for control over life Hastened death as a way of ending suffering "If then"
“Yes, I have thought many times, I want to get somebody from Exit, I also registered at Dignitas, because I thought: 'Yes, well, if it’s so unbearable that, that everybody around me has to hold their nose [due to tumour ulceration and smell]. That was the worst, I think, then I wanted to break off the exercise” (13).	Anticipation of future suffering WTHD as a way of sparing others from burden Hastened death as a way of ending suffering
“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... Dignity is that I have control over my body, when, when, not, 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” (1).	Loss of control Loss of independence Desire for control over life Loss of the self

	Loss of the sense of dignity Loss of meaning
"…and then this sleepiness and so on, and then at some point at the back of your mind you say: well, how long am I supposed to put up with this? And then it occurs to you: well, you don't have to, you can get out of it any time. But it's more of a reassurance […] It's a reserve" (12).	Loss of function Desire for control over life Hastened death as a way of ending suffering Hopelessness
"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" (5).	Desire for control over life
"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" (6).	Desire for control over life Ultimate control
"I have considered, I do like this physician-assisted suicide. With the assistance of a doctor, so you won't have a, a, messy death… and they [doctors] have said that any time I'm going to want to, it's up to me. That's right. I'm very glad about it. Yeah" (6).	Desire for control over life Fear of a painful death
"But it [WTD] is a ray of hope. You can say, if nothing works anymore and things are only getting worse, then you'd still have some way of shortening it" (12).	Hastened death as a way of ending suffering Suffering as something worse than death WTHD: unbearable situation with no way out (other than death) "If then"
"When I feel very, very, very wretched, this thought always returns: If you can't bear it any more, you can actually cut it short. Right at the last I just could [pause]… if it's even worse than it is now" (12).	Hastened death as a way of ending suffering Suffering as something worse than death WTHD: unbearable situation with no way out (other than death)
"If I would have such a pill in some drawer or the other, and I could take it on my own when I would have the feeling that nothing goes any more, then I would feel considerably better" (14).	"If then"
"[When metastasis was diagnosed] I immediately set about the option of Exit… because I said, I would like to have this possibility in any case. If for any reason it becomes unbearable for me, but I'm still not dying, then I would like to bring about my own death. And I saw to it all, that it was ready, that I had the prescription, and I talked to these people. That's sort of there on demand now" (13).	WTHD: unbearable situation with no way out (other than death)

5. Lived experience of timeline toward dying and death	
"I just want to get it over with… Tomorrow is the same thing, the same thing" (6).	Despair Suffering Tiredness Hopelessness
5.1 Anticipation of a painful death or agony	
"AIDS, that's probably -seeing as I'm 41- that's probably what I'm going to die of. That is going to be a very painful death. It is painful, I've seen it. It's painful, it's sad, it's lonely in a way, that you can be surrounded be all the loving people on your life, but you, it's lonely because you're gradually rotting away, your flesh is rotting, I hope to God in a way that your mind is rotting with it, because then you become totally, you don't know what's going on" (1).	Progressive deterioration Anticipation of a painful death Uncertainty
"It'll be extremely terrible. It'll be coming up from here, 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" (4).	Anticipation of future suffering Progressive deterioration Fear of suffering
"I am not afraid about death. I am only afraid of an agonizing death. Taking too much time" (14).	Anticipation of a painful death Fear of the dying process Suffering as something worse than death
"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" (6).	Fear of suffering Fear of the dying process
5.2 Progressive deterioration	
"This sort of disease ultimately leads to death. I have to walk that path" (4).	
"You lie on a bed and none of the normal functions come back. They will never come back and it will only get worse" (9).	Loss of function
"And I would not want to go through this as a daughter (of a patient). Sit down every day and watch how somebody is running towards death, lying there and finally waiting to be released" (14).	Not wanting to lose one's own value in the eyes of others
5.3 Uncertainty	
"I haven't been in hospital before. I wouldn't know the facts. I haven't been ill before" (4).	Fear
"Yes, and that is this uncertainty. You can plan nothing and, let me say, only on short notice, for very short distances" (14).	Loss of control
5.4 Ambivalence	
"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" (3).	Ambivalence WTHD as a will to live

REFERENCES

1. Lavery J V., 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(9279):362–7.

2. Kelly, B., Burnett P, Pelusi D, Badger S, Varghese F, Robertson M. Terminally ill cancer patients' wish to hasten death. Palliat Med 2002;16:339–45.

3. Coyle N, Sculco L. Expressed desire for hastened death in seven patients living with advanced cancer: a phenomenologic inquiry. Oncol Nurs Forum 2004;31(4):699–709.

4. Mak YYW, Elwyn G. Voices of the terminally ill: uncovering the meaning of desire for euthanasia. Palliat Med 2005;19(1):343–50.

5. Pearlman RA, Hsu C, Starks H, Back AL, Gordon JR, Bharucha AJ, et al. Motivations for physician-assisted suicide. J Gen Intern Med 2005;20(3):234–9.

6. Schroepfer TA. Mind Frames Towards Dying and Factors Motivating Their Adoption by Terminally Ill Elders. J Gerontol 2006;61(3):129–40.

7. 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(2):165–71.

8. Nilmanat K, Promnoi C, Phungrassami T, Chailungka P, Tulathamkit K, Noo-urai P, et al. Moving Beyond Suffering: the Experiences of Thai Persons With Advanced Cancer. Cancer Nurs 2015;38(3):224–31.

9. Dees MK, Vernooij-Dassen MJ, Dekkers WJ, Vissers KC, van Weel C. “Unbearable suffering”: a qualitative study on the perspectives of patients who request assistance in dying. J Med Ethics 2011;37(12):727–34.

10. Stiel S, Pestinger M, Moser A, Widdershoven G, Lüke U, Meyer G, et al. The Use of Grounded Theory in Palliative Care: Methodological Challenges and Strategies. Palliat Med 2010;13(8):997–1003.

11. Ohnsorge K, Keller H, Widdershoven G, Rehmann-Sutter C. Ambivalence’at the end of life How to understand patients’ wishes ethically. Nurs Ethics 2012;19(5):629–41.

12. Ohnsorge K, Gudat H, Rehmann-Sutter C. What a wish to die can mean: reasons, meanings and functions of wishes to die, reported from 30 qualitative case studies of terminally ill cancer patients in palliative care. BMC Palliat Care 2014;13(38).

13. Ohnsorge K, Gudat H, Rehman-Sutter C. Intentions in wishes to die: analysis and a typology – A report of 30 qualitative case studies of terminally ill cancer patients in palliative care. Psycho-Oncology 2014.

14. Pestinger M, Stiel S, Elsner F, Widdershoven G, Voltz R, Nauck F, et al. The desire to hasten death: Using Grounded Theory for a better understanding “When perception of time tends to be a slippery slope.” Palliat Med 2015;29(8):711–9.

15. Noblit G, Hare R. Meta-ethnography: Sinthesizing qualitative studies. Sage, 1988.

16. Monforte-Royo C, Villavicencio-Chávez C, Tomás-Sábado J, Mahtani-Chugani V, Balaguer A. What lies behind the wish to hasten death? A systematic review and meta-ethnography from the perspective of patients. PLoS One 2012

Jan;7(5):e37117.

17. 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(1):75–81.

Cuarto artículo: Assumptions and moral understanding of the wish to hasten death: a philosophical review of qualitative studies

Presentación del cuarto artículo de esta tesis:

Como se ha dicho, la aspiración incicial de esta tesis fue abordar el fenómeno del DAM –junto con los temas de la dignidad y de la autonomía- desde una mirada empírica y a la vez filosófica-antropológica.

Verdaderamente el tema de la muerte y su anticipación es tan inabarcable como apasionante, de forma que fue difícil encontrar un tema que pudiera ser de interés filosófico-antropológico y que a la vez pudiera ser una aportación para los profesionales de la salud que se enfrentan a situaciones de final de vida.

En la literatura del ámbito biomédico es frecuente la alusión a la necesidad de explorar los aspectos biográficos y culturales para entender el significado de, en este caso particular, el DAM. De esta forma, tras muchas conversaciones con el Dr. Xavier Escribano, horas de lectura de sus recomendaciones bibliográficas y tras mi estancia de investigación en Holanda en la que pude trabajar con al Dr. Evert van Leeuwen, surgió la idea de aprovechar el material valioso de las citas de los participantes de los estudios cualitativos sobre el DAM y profundizar en algunas de las coordenadas culturales y morales que los pacientes reflejan a través de sus expresiones verbales.

De nuevo este artículo no pretende ser sistemático ni exhaustivo, sino un análisis reflexivo sobre la realidad vivida de los pacientes.

Assumptions and moral understanding of the wish to hasten death: a philosophical review of qualitative studies

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Abstract

It is not uncommon for patients with advanced disease to express a wish to hasten death (WTHD). Qualitative studies of the WTHD have found that such a wish may have different meanings, none of which can be understood outside of the patient's personal and sociocultural background, or which necessarily imply taking concrete steps to ending one's life. The starting point for the present study was a previous systematic review of qualitative studies of the WTHD in advanced patients. Here we analyse in greater detail the statements made by patients included in that review in order to examine their moral understandings and representations of illness, the dying process and death. We identify and discuss four classes of assumptions: 1) assumptions related to patients' moral understandings in terms of dignity, autonomy and authenticity; 2) assumptions related to social interactions; 3) assumptions related to the value of life; and 4) assumptions related to medicalisation as an overarching context within which the WTHD is expressed. Our analysis shows how a philosophical perspective can add to an understanding of the WTHD by taking into account cultural and anthropological aspects of the phenomenon. We conclude that the knowledge gained through exploring patients' experience and moral understandings in the end-of-life context may serve as the basis for care plans and interventions that can help them experience their final days as a

meaningful period of life, restoring some sense of personal dignity in those patients who feel this has been lost.

INTRODUCTION

It is not uncommon for patients with advanced disease to express a wish to hasten death (WTHD) (Monforte-Royo et al. 2011). Although the WTHD is regarded by some authors as being synonymous with notions such as allowing a life-ending process to take its course, letting go, acceptance of dying, moving on to another reality, being tired of living or rational suicide (Ohnsorge et al. 2014a), this is not necessarily the case. Indeed, we would argue that a distinction needs to be made between the WTHD expressed in the specific context of a disease process and a general wish to die that may have different degrees of intentionality, ranging from a generic desire that does not necessarily imply taking steps towards ending one's life to a formal request for euthanasia. Furthermore, the WTHD may vary in intensity over time, indicating the ambivalence that many patients feel about their situation. Some authors also point out that the WTHD can signify for patients something other than an actual wish to die: for instance, it may be the expression of a wish to live but not in this way (Monforte-Royo et al. 2012).

Rehman-Sutter et al. (2015), quoting Chochinov, ask whether the WTHD should be considered part of a normal adaptation to a life-threatening disease, and if so, where is the line between normal and pathological. As these authors point out, the answers to these questions transcend the medical sphere and "depend on philosophical assumptions about the normative significance of end-of-life care and of dying" (Rehman-Sutter et al. 2015: 5). They go on to say that in arriving at what we wish for "we evaluate and re-evaluate our moral understandings, self-images, convictions, and deepest commitments" concerning life and death (Rehman-Sutter et al. 2015: 8).

As noted above, the expression of a WTHD may sometimes be confused with a request for euthanasia or assisted suicide. In Western societies there has been intense debate among clinicians, ethicists and the general public regarding whether or not such practices should be decriminalised. One feature of this debate has been the emergence of notions such as self-appointed death, self-chosen death or self-determined death, indicative of a certain change in mentality and attitudes, of an attempt to normalise death as a voluntary act. This highlights how the way in which we talk about death and dying is both a cause and a consequence of our ideas about suffering and death, ideas that presuppose and generate moral understandings that are circumscribed to particular situations.

All this suggests that the WTHD cannot be understood without taking into account the socio-cultural context and the moral understandings of those patients who express such as wish. Margaret Walker (2007) defines moral understanding as the background against which people define themselves, act in relation to others and understand the world. Our behaviour as individuals will also be influenced by the judgements, ideas and expectations that others have of us (Ohnsorge et al. 2012). Thus, as Walker puts it, our identity, our sense of who we are, is a narrative that "is threaded through by another story, one about 'what this means'. The last involves a history of moral concepts acquired, redefined, revised, displaced and replaced, both by individuals and within some communities of shared moral understanding" (Walker 2007: 119-120).

In light of the above, the aim of the present study was to analyse the moral understandings of patients who express a WTHD (as well as those of their relatives and healthcare professionals, where such data were reported). The starting point for this analysis was a recent systematic review and meta-ethnography conducted by our group of 14 qualitative studies on the WTHD in advanced patients (Rodríguez-Prat et al.

2017). The results of that review indicated that a WTHD can only be understood by considering the meanings that patients ascribe to it, in other words, what it is that they really desire or wish to communicate when they express such a wish. The present study returns to the studies included in our previous review in order to analyse in greater detail the verbatim statements made by participants. Our goal in doing so was to show "how meaning is personally attributed and to examine the moral reasoning that people make use of when expressing certain preferences" (Ohnsorge et al. 2012: 631).

METHOD

The starting point for this study was the aforementioned systematic review and meta-ethnography on the WTHD in patients with life-threatening illness (Rodríguez-Prat et al. 2017). The search strategy used in that review applied a combination of MeSH and free-text terms to the Pubmed, Web of Science, CINAHL and PsycINFO databases. Fourteen qualitative studies were finally included, involving a total sample of 280 participants (patients, families and healthcare professionals). These studies had been carried out in Australia (Kelly et al. 2002), Canada (Lavery et al. 2001; Nissim et al. 2009), China (Mak and Elwyn 2005), Germany (Pestinger et al. 2015; Stiel et al. 2010), The Netherlands (Dees et al. 2011), Switzerland (Ohnsorge et al. 2014a, 2014b, 2012), Thailand (Nilmanat et al. 2015) and the USA (Coyle and Sculco 2004; Pearlman et al. 2005; Schroepfer 2006). For more detailed information about the method used in the systematic review, see Rodríguez-Prat et al. (2017).

Meta-ethnography (Noblit and Hare 1988) is an inductive process in which systematic and constant comparisons are made between the concepts found in different studies, the goal being to obtain an interpretive synthesis or critical understanding of a given phenomenon based on multiple facts, cases and narratives. In the case of our previous review of qualitative studies on the WTHD the meta-ethnographic method enabled us to propose an explanatory model of the phenomenon from a clinical point of view. In addition, we observed that the majority of the verbatim statements made by patients who expressed a WTHD reflected assumptions that could be organized within a common frame of reference. More specifically, examination of these statements led us to identify four types of assumptions that generally feature in both clinical and ethical-philosophical discourses in the end-of-life context, and which, from an ethical-philosophical point of view, can help to understand in greater depth the personal background of these patients:

1. Assumptions related to patients' moral understandings in terms of dignity, autonomy and authenticity.
2. Assumptions related to social interactions in terms of how others assign value to the individual and to the individual's life in the context of an illness (related to the notion of social dignity).
3. Assumptions related to the value of life, in terms of what makes it worthy or unworthy (assigning value and meaning to life).
4. Assumptions related to medicalisation as an overarching context within which the WTHD is expressed.

In the sections that follow, we operationalise each of the first three classes of assumptions, offering a conceptual framework for understanding them in the end-of-life context and for linking them to the statements made by patients in the reviewed primary studies of the WTHD. In addition, and given that a person cannot be understood in isolation from his or her embodied and contextual reality, we also examine those statements which make reference to medicalisation as an overarching framework within which many patients experience and attribute meaning to their illness. Consequently, the fourth class of assumptions, those related to medicalisation, are considered not separately but as a thread running throughout each of the other classes. With the aim of illustrating each of the concepts that we develop, Table 1 lists some of the most representative quotes taken from primary qualitative studies of the WTHD.

Table 1. A selection of quotes from primary studies of the WTHD

Themes and subthemes	**Moral self-understandings**	**Images of medicalisation**
"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 [sic] 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" (Lavery et al. 2001).	- Dignity understood as being autonomous, independent. - Former self: assumption of a previous self (authentic self *vs*. ill self).	- Loss of self in illness. - Being dependent on life-support machines.
"I say: I have made my decision. I don't want you to treat me any longer. Someone says, now you are probably too weak for chemo. I say: if I'm not too weak and they want to give me chemo, I will refuse it, because in the little time that is left to me I want quality of life, not quantity of life. I decided that a year ago: if this were to overcome me, then that's what I would choose" (Dees et al. 2011).	- Self-agency. - Authenticity achieved through decision-making capacity. - Worthy life: quality of life.	- Quality of life *vs*. quantity of life. - "Medical invasion": power of medicine.
"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" (Pearlman et al. 2005).	- Idea of the preservation of the self (split identity: image of the person before and during the illness). - There is some kind of inner authenticity that needs to be preserved when facing others. - Social dignity: how the person is seen by others and a sense of maintaining the self in the eyes of others.	- Social identity: illness limits your life.
"Finally the illness that dominates everything will wipe out all life has to offer me, what I feared most is exactly what will happen to me. I won't belong anymore, the emptiness of existence, the lack of independence, being unable to do things myself, being at the mercy of others whom I will have to beg to do the things I need in a way that's suitable	- Loss of value of life (emptiness of existence) due to the lack of independence. - Value of oneself (dignity): being able to do things on your own.	- Representation or anticipation of future suffering. - Life is unenjoyable in illness. - Illness that dominates everything.

for me” (Dees et al. 2011).		
“And I don’t feel this is a life for me [pause], carrying on living like this. That’s why [pause] um, I am [pause] very – how should I put it, so you understand me – I’m on the road, on the move a lot and [pause] then I thought, if I can’t live like before, life has no value, does it? And [pause] I drove my car a lot, and I can’t do that anymore either. […] Yes, did a lot of travelling. […] I feel my life isn’t worth anything at all any more, if I just lie here and wait” (Ohnsorge et al. 2014a).	- Split identity (before and during the illness). - Life as not worth it (no dignity): life has no value, it is not worth it if the possibility of carrying out meaningful activity is lost.	
“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**...** Dignity is that I have control over my body, when, when, not, 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” (Lavery et al. 2001).	- Dignity as having control over life. - Dignity as self-determination.	- Possibility of deciding when life is over: (“it is not a virus that is going to take my life”).
“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 a vehicle to just, just stop my life” (Coyle and Sculco 2004).	- Life with pain is not worth it (in some circumstances it would be preferable to die).	- Possibility of deciding when life is over. - Death is preferable to suffering: “pain as the biggest fear”.
“... It should be up to me to decide… when I’ve had enough suffering... One of my landmarks, if I’m at the point where all I can do is lie on a bed all day long, then to me that’s probably not living anymore” (Pearlman et al. 2005).	- Values: own decision-making: not worth living if losing functionality and independence.	- Suffering as something worse than death.
“I immediately turned to the option of Exit [pause], because I said I’d like to have this option whatever happens. If things become unbearable for me for some reason, but I’m still not dying, then I’d like to be able to grant myself my own death […] This is really only about ending a situation that has become unbearable, and not having to rely on either being hit by another stroke or some doctor being understanding after all. I want to be able to keep this in my own hands for when the moment comes. I was a very self-determined person all my life, and that’s very important to me” (Ohnsorge et al. 2014a).	- Life is not worth it if in pain. - Dignity as self-determination: “grant myself my own death”; “keep this in my own hands”.	- Possibility of having some control over the dying process: “I want to be able to keep this in my own hands”.
"He didn't want to kill himself: he didn't want to die. It was about finding any method to be vital and the list was narrowed down to the most- the simplest things, and when they were gone, he didn't have a reason… so it wasn’t just the diarrhea or the lack of driving: it was just losing, like his definition -what his sense of vitally was. And when that was gone, then he was ready” (Pearlman et al. 2005).	- No way of maintaining an authentic self (losing the self). - Dignity as being able to do ordinary activities related to being oneself (preservation of the self).	- Illness seen as a process of loss.

"[When metastasis was diagnosed] I immediately set about the option of Exit … because I said, I would like to have this possibility in any case. If for any reason it becomes unbearable for me, but I'm still not dying, then I would like to bring about my own death. And I saw to it all, that it was ready, that I had the prescription, and I talked to these people. That's sort of there on demand now" (Ohnsorge et al. 2014b).	- Autonomy and self-determination as core values.	- Having some control over death: "bring about my own death" (if things get worse).

1. ASSUMPTIONS ABOUT MORAL UNDERSTANDINGS

The specific meaning ascribed to suffering, pain, illness and death varies across cultures (Illich 1976; Le Breton 1999; Morris 1991). In Western societies the social representation of these phenomena (i.e. how society conceives of or experiences them) is closely linked to the birth of modern medicine and to what is known as medicalisation (Clark 2002; Illich 1976; van Wijngaarden et al. 2016), the process whereby "'non-medical' problems become understood and treated as 'medical' problems" (Conrad 2008: 5). Through this social process, natural phenomena such as illness, death and mourning become redefined and articulated within the framework of a medical paradigm. With respect to the WTHD there are four points to consider in relation to medicalisation. First, if the latter means that the normal challenges of life become treated as medical problems, then natural stages of our experience, such as illness and the end of life, may be regarded as problems to be solved by medical science. In this regard, some authors have linked the medicalisation of death and dying to a growing faith in the ability of science, rationality and progress to offer solutions to what were previously regarded as normal features of human life (Conrad 2008). One example of this would be the prescription of drugs to someone experiencing sadness at the loss of a loved one, even though the person in question does not have a medical problem (Parens 2013). The second point is that the medicalisation process may lead us to lose sight of the subjective dimension of the person; the 'patient' thus becomes treated as an 'object' whose problem can be solved (Parens 2013), rather than as someone located in a particular context, a person with beliefs, values and the ability to act in accordance with them. Third, a medicalised view may lead to physician-assisted suicide and euthanasia being seen as the "technological solution to the problem of death and (feared) suffering in the shape of a very effective lethal injection" (van Wijngaarden et al. 2016: 266). The results of our aforementioned systematic review suggest that death may be seen by patients as a way of escaping suffering, and thus medical intervention, backed by the law, would become the means through which this wish is realised. Finally, and as pointed out by Wijngaarden et al. (2016), the fact that clinicians have to make decisions about how a person's life may be prolonged or shortened can influence patients' own view of their illness. For example, some patients may reject their dependence on life-support machines, due to the loss of quality of life that is implied. Consequently, a loss of control or autonomy may, for some patients, be a reason why they wish to die.

Within a context of medicalisation, therefore, the identity of the ill person may be redefined through, for example, the use of drugs that affect cognitive functioning or dependency on life-support machines or systems. With regard to the latter, Ariès (1975) offers an illustrative quote from the Jesuit historian François de Dainville, whose response to being intubated in an intensive care unit was to state: "I am being deprived of my death".

Among patients who expressed a WTHD in the studies included in our review, the fear of becoming dependent on life support machines was sometimes the result of personal experience or of having witnessed such a situation in a loved one: "My first husband, he suffered a long time. He had on those machines, and I used to say, 'God,' I said, 'don't let me go under those machines" (Schroepfer 2006: S135). Other patients saw it as inevitable that someone in their condition would not wish to be dependent on technology. For example, one man said that his need for artificial ventilation prevented him from enjoying everyday activities, which for him were what brought a sense of dignity to his life (Lavery et al. 2001). Another patient felt that dependency on medical interventions of this kind raised questions about the meaning of life: “Someone with a tube sticking up the bottom, a tube sticking into the nostrils, another somewhere else. I mean, what for? Can you save them?” (Mak and Elwyn 2005). These statements illustrate how medical and technological interventions may influence a person’s experience of illness and potentially contribute to the WTHD. However, this is not necessarily the case for all patients who express a WTHD, many of whom will be fully competent when they discuss such a wish, even though there may have been other times when they were not, due to the treatment they required.

Some of the statements made by participants in the studies reviewed enabled us to identify social representations of death and suffering, linked in part to the overarching context of medicalisation. For instance, some patients referred to their body as a broken machine, and death as the proof that this machine could not be repaired. In another recurrent image the end of life was seen as a process of intense and prolonged suffering, due to the technological possibility of keeping a person alive: “I am only afraid of an agonizing death. Taking too much time” (Pestinger et al. 2015: 715). In a medicalised context this, according to Callahan (1989), has to do with exchanging a short life and a fast death for a long life and a slow death.

Having introduced the contextual framework of medicalisation we will now seek to illustrate how the statements made by patients reflect assumptions about their own value as individuals and their moral understandings. Specifically, we will examine assumptions about dignity, autonomy and authenticity. It will be seen how each of these three classes of assumptions can help to understand the premises on which an individual attributes value to his or her life.

1.1. Assumptions about dignity (the value of oneself)

In the 1950s the term ‘dignity’ began to be used in the palliative care context to refer to a new attitude towards the care and condition of patients (Clark 2002). The idea of dignity has since grown in importance, and safeguarding this aspect of a patient’s life has become a key objective in clinical practice (Chochinov et al. 2002; Guo and Jacelon 2014; Östlund et al. 2012; Street and Kissane 2001). Many studies of dignity in the end-of-life context refer to it in ontological terms, such that dignity is understood as an intrinsic and inalienable value of human life, as something common to all persons which is not altered by circumstances (Leung 2007; Pullman 1996; Steinhauser et al. 2000; Sulmasy 2005).

On another level, however, dignity may be conceived of as an empirical and dynamic quality, as part of the person’s sense of identity in relation to physical, psychological, spiritual and social factors, all of which will be mediated by the experience of illness (Chochinov et al. 2002; Street and Kissane 2001). Although these two levels are sometimes discussed separately, they are not mutually exclusive and dignity may be conceived of as an ontological foundation on which the empirical aspect is constructed. Dignity can also be understood in terms of value, in the sense of the value that people attribute to their life at a given moment, together with the factors that make life something worth valuing. Chochinov et al. (2002) note that dignity overlaps with concepts such as pride, self-respect, quality of life, well-being, hope and self-esteem, as well as with the extent to which a person perceives him or herself to be worthy of honour and esteem from others. Here we have assumed that dignity is a dynamic quality that is nonetheless founded on an intrinsic and inalienable feature of human life, and as such it is similar to the value that a person attributes to him or herself (i.e. the sense of self-worth). Thus, for the present analysis we identified statements in which patients made some reference to the notion of self-worth and then analysed them in light of our operationalised definition of dignity.

Illness, which for many of the participants in our review was perceived as the first steps towards death, was the defining context of lived experience for those who expressed a WTHD (Kelly et al. 2002). Thus, their perception of personal dignity was mediated by the fact of being ill. In a context of medicalisation, and in terms of what Kellehear (2007) refers to as social death, one might say that the person begins to die in illness. This would certainly be consistent with an observation made by Pearlman et al. (2005: 236), who noted that “patients and their families viewed functional losses as markers of the patient’s transition from life to death”. The notion of social death is also interesting because it offers a framework for understanding the tendency for some societies to exclude people once they are no longer productive or autonomous, or have become a burden on others. This individualistic attitude towards the value of human life, which is characteristic of Western society, for example, can also be seen in new attitudes towards death (Taylor 1992): death as the loss of self (of one’s individuality). And if, as was suggested above, death begins with illness, then a loss of self will also occur when the patient receives a diagnosis. It is then that the patient will begin to stop living, despite his or her wishes: “[I] wish to live but can’t live” (Mak and Elwyn 2005: 345).

Many of the statements made by patients who had expressed a WTHD reveal ideas, value judgments and assumptions about their identity (who am I?) and self-worth (what they believe gives value to their life). When talking about their reasons for wishing to die, many of them, both explicitly and implicitly, referred to the notion of dignity as we defined it above (i.e. as a dynamic concept). For the majority of participants the value they attributed to life (their sense of dignity) was seen as something they could lose in the state of vulnerability brought about by their illness (Dees et al. 2011; Lavery et al. 2001; Pearlman et al. 2005). As the disease progressed they began to lose control over bodily functions and became dependent on others to perform certain everyday tasks (going to the toilet, taking a shower, getting dressed, eating, etc.). In some cases the loss of dignity was also linked to their anticipating a future in which they would lose their intellectual capacity or even conscious awareness (Dees et al. 2011; Pearlman et al. 2005; Pestinger et al. 2015). Their advancing illness was thus experienced as all-consuming, as a process in which aspects of the self would be progressively lost until nothing was left (Dees et al. 2011; Kelly et al. 2002; Lavery et al. 2001; Nissim et al. 2009; Ohnsorge et al. 2014a; Pearlman et al. 2005).

In this context, a hastened death was seen as a way of ending the loss of self, which was often synonymous with a perceived loss of dignity. For these patients, illness had stripped them of all that had been meaningful in their life, and some of them expressed their fear of being reduced to the status of a vegetable (Lavery et al. 2001; Pearlman et al. 2005). Others sometimes felt that their illness was something to be hidden (Dees et al. 2011), or spoke of the dying process as messy and undignifying (Schroepfer 2006). Seen as the end of all possibility, the loss of self was described by participants as a destructive enemy to be feared (Dees et al. 2011; Kelly et al. 2002; Nissim et al. 2009; Pearlman et al. 2005).

An increasingly mechanistic view of the body has also had an impact on representations of illness. The body is seen as something that can be repaired, and pain as an external factor capable of dehumanising the person: "All of a sudden, it dawned on me that there was no solution, and if there was no solution to my cancer, then why was I hanging around? I got thinking about death as a practical matter. Why hang around and cause a lot of people a lot of grief?" (Coyle and Sculco 2004: 704). In this context, Walter (1994) argues that the metaphor of death as the Grim Reaper has been replaced with a factual representation of death as a killer disease. This paves the way for the myth of the physician who fights death (Illich 1976), and if the latter occurs it is because medicine has been unable to solve the technical problem of illness.

1.2. Assumptions about autonomy

The debate in some countries over whether euthanasia or assisted suicide should be decriminalised has raised the possibility of people being killed on request. This kind of medicalised control over the dying process implies a shift from the idea of death as something natural and inevitable that all must suffer to death as something to be mastered or brought under technological control (Ariès 1975). The transition from life to death thus becomes a matter of choice due to the authority of the self, the latter having replaced older sources of authority such as the will of God or doctor's orders (Walter 1994). This is also reflected in the tension between 'loss of control' and the 'desire for self-determination' that emerges in a context of medicalisation (Quill and Battin 2004; Walter 1994; White and Callahan 2000). Whereas loss of control would be a consequence of having to follow doctor's orders, the desire for self-determination would be an expression of what Walter (1994: 54) refers to as the authority of the self: "I did it my way".

The statements made by patients who expressed a WTHD show how the apparent power of medicine to control death and dying has given rise to two opposing and related scenarios. On the one hand, many people fear that their life will be prolonged under poor and artificial circumstances, a situation which they imagine will be accompanied by pain and a loss of both control and, perhaps, dignity (Brody 1989;

Callahan 1989; White and Callahan 2000). Medical intervention may thus be seen as something that exerts a high price, draining the patient of energy and impeding the natural process of dying: “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” (Nissim et al. 2009: 169).

In response to the perceived loss of control, many patients expressed a desire for self-determination, the right to decide when and how their life should end, which paradoxically would most likely require medical intervention: “I don’t want to deal with it so I think I would speed up things myself. I don’t want to be lingering here in palliative care, lying day and day, slowly dying. Oh no, I don’t want to do that. So, suicide is a way of exiting. I don’t want to talk about that because I like life and I have lots to live for, but if I come to the point when I am too weak to do anything, then I don’t want to stay" (Nissim et al. 2009: 168).

Whereas suffering and pain were seen as placing limits on the possibility of an enjoyable life, personal agency was invoked as a way of having some control over the dying process, in this case, by removing suffering through death: “how long am I supposed to put up with this? And then it occurs to you: well, you don’t have to, you can get out of it at any time” (Ohnsorge et al. 2014a: 10). In other cases, autonomy was regarded as the value or quality that underpinned and defined the sense of personal dignity, and for these patients ‘keeping it in their own hands’ was what defined them as persons.

1.3 Assumptions about authenticity

Authenticity has traditionally been understood in different ways. In the broad sense it has to do with being “faithful to an original [or a] reliable, accurate representation […] To say that something is authentic is to say that it is what it professes to be, or what it is reputed to be, in origin or authorship” (Varga et al. 2016: 1). This definition is consistent with a view widely expressed in the end-of-life context, whereby those who find themselves in this situation can — and should — be able to make decisions that reflect the person they profess to be. Although, from a normative point of view, it is difficult to determine the basis of authenticity, one of the arguments that is often made in support of a voluntary death is that patients’ thoughts, desires and actions should be respected as authentic expressions of who they are (Quill and Battin 2004).

The statements made by patients who expressed a WTHD reveal that the idea of authenticity often appears in the form of what one might call a ‘split identity’, in other words, the self before and after the onset of illness. In fact, some patients specifically described themselves in terms of a ‘former self’ and an ‘ill self’ (Coyle and Sculco 2004; Dees et al. 2011; Mak and Elwyn 2005; Nilmanat et al. 2015; Nissim et al. 2009; Ohnsorge et al. 2014a, 2014b). The former self was viewed as the authentic (and dignified) self that wished to live, as the true person and as how the patient wished to be remembered. By contrast, the ill self was described by the same patients as useless, as having lost the will to live due, for example, to a diminished quality of life. Allusions to the ill self were thus often made when patients spoke about not wanting to be remembered as someone depleted and dependent on others. Conversely, certain actions, such as deciding to refuse further medical treatment, were seen as ways of maintaining the authentic self in spite of the illness.

Autonomy was at times seen as an aspect of authenticity, since some patients experienced illness as being in opposition to their autonomous (authentic) self and as exerting control over their circumstances. The wish to have some control over the dying process was thus described in terms of preserving the authentic self ("I am in control of this body. This is mine, I will do whatever I want to do with it" [Schroepfer 2006: S136]), or in terms of dignity ("dignity is that I have control over my body [it is] 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" [Lavery et al. 2001: 365]). In this context, some patients spoke of 'granting myself my own death (if things get worse)' as being the last act that a human being can perform in the name of authenticity.

2. ASSUMPTIONS ABOUT SOCIAL INTERACTIONS

In relation to what we referred to earlier as 'social death', the way an individual is seen by others plays a crucial role in the construction of his or her identity. In the context of medicalisation there are two issues that are especially relevant in terms of social interactions: the transfer of care and the idea of being a burden on others. When care of the dying was transferred to the hospital setting (such that this is where death occurred) the role of accompanying the dying person passed from relatives or priests to doctors (Ariès 1975; Walter 1994). The end-of-life was thus confined to a medical context, a private, hygienic and technological environment (Walter 1994). For the family, the removal of death from the home meant that they could no longer perform the rites and rituals associated with care of their dying relative. As a result, death not only ceased to be a part of people's domestic experience but also became an object of taboo, an unpleasant thing to be avoided (Gorer 1955). The doctor became the new master of ceremonies of this scenario, controlling the process of dying and administering drugs in order to deprive patients of the experience (Illich 1976; Walter 1994).

The equating of being ill with being a burden on others has become widespread within this context. One of the consequences of medicine being seen as a way of combating death (Callahan 1989) was that the dying process gradually ceased to be seen as part of normal human experience, as a final stage of life through which the person would be accompanied and cared for. The loss of this kind of care narrative, in which accompanying the dying person was seen as a meaningful act, is one of the factors that has led to ill people in the modern age being regarded as a burden.

The impact of interpersonal relations — the importance the individual gives to how others see and value him or her — was evident in many of the statements made by patients who expressed a WTHD, as well as by relatives and healthcare professionals. It is interesting to note that in many cases the WTHD was linked to patients' beliefs about the value judgments of others (i.e. you think that others believe you are a burden to yourself and others, that you're no longer worthy and suffering unbearably) (Coyle and Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Lavery et al. 2001; Mak and Elwyn 2005; Nissim et al. 2009; Ohnsorge et al. 2014a, 2014b, 2012; Pearlman et al. 2005; Schroepfer 2006; Stiel et al. 2010). In fact, of the 122 quotes reported in the studies reviewed, 43 referred to the patient's social context. Of these, 15 made reference to the role of relatives and healthcare professionals in the patient's experience. The remaining 28 quotes, however, referred to patients' assumptions about how others would view them in terms of dignity (personal value) and the value of their life (Coyle and Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Lavery et al. 2001; Mak and Elwyn 2005; Nissim et al. 2009; Ohnsorge et al. 2014a, 2014b, 2012; Pearlman et al. 2005; Schroepfer 2006; Stiel et al. 2010). In other words, the majority of quotes in which the social context was referred to as a factor in the WTHD concerned how patients believed they were seen by others.

Many of these statements had to do with what one might call social dignity. Thus, not wanting to be seen by others as ill and frail, and the wish to preserve or maintain the self in the eyes of others was a common concern among these patients. In addition, the idea that their illness would also affect those around them was linked for some patients to a wish to avoid making others suffer. In such situations the WTHD arose as a way of sparing others from burden, as a form of altruism. This notion of social dignity was also related to the sense of belonging (Lavery et al. 2001). When patients felt excluded from their community or social groups as a result of their illness, this was often experienced as a rupture in their life story. A lost sense of belonging also occurred when patients could no longer fulfil a previous social role that had given meaning to their life. For one patient, the value she assigned to herself had to do with the experience of knowing that she was loved and needed by those around her (Lavery et al. 2001). She declared that life without love was what was causing her to lose any wish to keep on living.

3. ASSUMPTIONS ABOUT THE VALUE OF LIFE

Many of the statements made by patients alluded to reasons why life was no longer worth living. This attributing of value to life can be considered in terms of the Aristotelian distinction between *zoê* and *bios* (Aristotle 1995). *Zoê* denotes our biological existence, the ‘bare life’ that is common to us all. In this respect, the loss of control over bodily functions and diminished functional capacity leading to the loss of independence (aspects of *zoê*) was one of the main reasons cited by patients, relatives and even healthcare professionals for why life had lost its value (Coyle and Sculco 2004; Dees et al. 2011; Lavery et al. 2001; Mak and Elwyn 2005; Nilmanat et al. 2015; Nissim et al. 2009; Pearlman et al. 2005; Pestinger et al. 2015).

At times, however, the two views of life, *zoê* and *bios*, were intertwined within a single reality. This was the case, for example, when the suffering (which can be both *zoê* and *bíos*) caused by illness was given as one of the reasons why a patient had lost the will to live. Some patients stated that they would rather die than live with pain and suffering, because for them a life of pain was not worth living. It should be noted that the idea that life is no longer worth living cannot be understood within a purely biologistic framework (*zoê*). On the contrary, such an attribution requires a rational judgment (*bios*).

In Western society, ideas of transcendence or spirituality no longer provide a frame of reference for many people's lives (Taylor 1992), and thus the belief that death is the door to the afterlife and that suffering is God's retribution on this earth has waned. This contrasts with the centuries-old Christian view that man is a creature of God, and therefore is not master of his own life; one only has to think of the social condemnation of suicide or of the sick in medieval times, their final battle being to accept that their fate was in God's hands (Ariès 1975). According to Ariès (1975), the ideal death in the Middle Ages was one that allowed the dying person and those around him to prepare themselves, to become aware of the situation; one should die knowing that death was approaching, and thus a sudden death was viewed as the worst of punishments. This contrasts with what one observes in the statements made by patients in the qualitative studies we reviewed, for whom death was seen as a kind of salvation, as that which would release them from their present suffering (Coyle and Sculco 2004; Lavery et al. 2001; Nilmanat et al. 2015; Nissim et al. 2009; Ohnsorge et al. 2014a; Pearlman et al. 2005). Having lost quality of life they felt that the very value of life had been undermined, which some of them expressed in terms of a tension between quality of life and quantity of life (Dees et al. 2011). Other patients posed specific questions about the meaning of their suffering, asking, for instance, “why me?”, “why [am I] suffering so?”, “why [am I] hanging around?” (Coyle and Sculco 2004; Nilmanat et al. 2015; Nissim et al. 2009). For many of them, the WTHD emerged in response to a loss of meaning in life and of the will to live. Only a few patients held a somewhat more positive view of their illness, either as a result of their religious beliefs (Ohnsorge et al. 2012) or because their attitude was one of acceptance (Ohnsorge et al. 2012).

DISCUSSION

Thus far we have analysed the statements made by patients who expressed a WTHD in relation to different classes of assumptions. In this section we take a more critical look at the different areas of our analytical framework, namely: medicalisation; assumptions related to moral understandings: dignity (including social dignity), autonomy and authenticity; and the value of life.

Medicalisation

Parens (2013) argues that there are good and bad forms of medicalisation. The present philosophical analysis has mainly considered negative aspects, such as dependence on life support machines, the depersonalisation of death in the hospital context, or the use of drugs that prevent a person from being aware of the end of life. However, the statements made by patients also reveal the positive side of medical intervention, in that it can help to control pain or other symptoms of the illness. Thus, medical technology and integrative care can be combined to improve diagnosis or to develop the best interventions, and this can be done while respecting a person’s dignity or authenticity. A related issue here is that some patients related their WTHD to the experience of pain. Therefore, giving them medication to relieve pain or to treat symptoms of depression or other kinds of psychological distress may be one way of addressing the anguish and fear that they regard as triggering their WTHD.

It is also worth noting that many of the quotes (41 of 122) referred to the kind of future that patients imagined awaited them. While in some cases these ideas were influenced by their own past experience or that of a close friend or relative who had gone through something similar, for other patients they were the result of images of death and dying that were present in the cultural context (Pestinger et al. 2015). This highlights how important it is for healthcare professionals to understand the emotional distress (fear, anxiety, uncertainty, hopelessness) experienced by patients at the end of life, and to provide them with adequate information about their situation. In this respect, medicalisation can play a useful role in challenging some of patients' worst fears about the dying process, and may potentially help them to accept suffering and the final days of life as meaningful. Indeed, rather than being seen as a prelude to death in which the person is stripped of value, the end of life may also be an opportunity to establish deep bonds with loved ones, or to re-evaluate one's own identity in accordance with what the person considers to be important and meaningful.

Dignity

As we have seen, dignity was commonly experienced as a dynamic and subjective quality that could be undermined by the loss of functional capacity or the perceived loss of self. Interestingly, none of the statements made by patients referred to dignity as an intrinsic aspect of human life, despite the fact that such a definition often features in theoretical discussions of the concept. One might argue, however, that the labelling of certain experiences as undignified rests upon an a priori idea of an intrinsic dignity that has not been respected.

In this context, Charles Taylor (1989), among others, has highlighted the importance of mutual recognition — based on an idea of universal and egalitarian dignity — as a cornerstone of personal identity. In the clinical context, this kind of recognition would entail that a person's dignity is preserved through the care that he or she receives at a time of great vulnerability (i.e. I offer you the care you need because I respect you and recognise you as a person with dignity). This recognition of the patient as a human being (and thus, by definition, as a person with dignity) may go further towards protecting his or her dignity that would a conception of dignity based on those aspects of ourselves which we believe make us worthy (or not) of respect from others (Taylor 1989).

From the clinical perspective, the equating of dignity with autonomy can be linked to the ethical system of principlism, as developed in the Anglo-American context, which argues that autonomy is the pillar on which bioethical guidelines are founded. However, a slightly different view is present within European bioethics, which highlights the centrality of dignity and argues that it cannot be reduced to the concept of autonomy (Rendtorff 2002). For instance, the final project report on *Basic Ethical Principles in European Bioethics and Biolaw* identified dignity — alongside autonomy, integrity and vulnerability — as a framework for protecting the person from dehumanising technological developments. After examining and discussing the meaning of the concept, the report defined dignity as "a quality of the person as such. It now refers to both the intrinsic value of the individual and the intersubjective value of every human being in its encounter with the other. […] Dignity concerns both oneself and the other: I must behave with dignity, and I must consider the dignity of the other" (Kempt and Rendtorff 2008: 240). This definition could be used to guide both practice and policy in the end-of-life context, where the aim would be to ensure that advanced patients continue to be treated as human beings with inherent value. From a legal perspective it may be difficult to agree on what the implications of the notion of intrinsic dignity are (one has only to think of the vague definition of this concept that appears in the Universal Declaration of Human Rights [United Nations General Assembly 1948]), but recognising the other as a dignified human being is nonetheless a prerequisite for respecting the person in his or her entirety, especially when that person is rendered vulnerable by advanced disease.

The privatisation of death in modern society can mean that it becomes an anonymous event happening to an uninformed individual (the patient) who has no control over his or her final days. Dying in hospital may thus deprive the person of the respect and dignity that he or she deserves. The title of a recent research paper is revealing in this respect: ‘Do the circumstances allow for a dignified death?’ (Jors et al. 2014). As we have seen in some of the patient quotes, the immediate environment of persons facing the end of life does not always leave them feeling valued or cared for, and thus we could say that the circumstances do influence a person’s sense of dignity. This suggests that considering the impact which aspects of the environment (treatment by doctors and nurses, respect for privacy, etc.) can have on a person’s sense of dignity is important not only for developing personalised care plans, but also for ensuring that the training received by health professionals equips them to recognise the dignity inherent to each individual. However, the ability of patients themselves to recognise that dignity is a quality they possess simply by being human can also help them to maintain a sense of personal dignity despite their illness (Rodríguez-Prat et al. 2016). Ultimately, it is not the circumstances that determine a ‘dignified death’, but rather the person who, through his or her values and beliefs, attributes value and meaning to life and to the self.

An alternative to hospitalised death can, of course, be found in the hospice movement, whose philosophy is to offer compassionate and holistic care (from pain management to emotional and spiritual support) to people facing a life-limiting illness.

In our systematic review of qualitative studies on the WTHD the samples of patients were drawn from a variety of settings (in- and outpatient palliative care units, hospices, large cancer centres and nursing homes). However, we were unable in that review to determine the possible influence of the setting on patients’ experience, as this would require a more detailed analysis of primary study data.

Autonomy

A narrative of self-determination could often be observed among those patients who, faced with the end of life, expressed a strong desire to take control of their circumstances and the process of their illness. For these individuals, losing control over their life and seeing the illness affect their functional and cognitive ability, undermining their ability to make decisions and to live as they would wish, was itself experienced as a form of suffering, as ceasing to be themselves. In situations such as these it can be important for health professionals to draw attention to the idea of intrinsic dignity, as this may help patients to hold on to something that goes beyond their identification with the ill self, with the person who has lost the most profound and authentic aspects of his or her identity.

A further point has to do with what might be called a culture of emancipation focused on individual experience and the rights of patients, as from this perspective the WTHD might perhaps be understood as an expression of individual liberty that occurs against a background of medicalisation. Based on our analysis, and in agreement with van Wijngaarden et al. (2015), we would argue that this culture of the individual with a strong desire for self-determination could also be seen as a reaction against medicalisation. In other words, the fact that medicalisation places advanced patients in a situation that they may experience as dehumanising, due to their dependence on life-support machines, drugs and medical professionals, etc., may provoke in these patients a strong desire for autonomy, for the ability to decide how they will see out their final days.

Authenticity

Our analysis of patient statements indicated that being authentic was equated with being independent and capable of making decisions in keeping with one's life to date. Through what we referred to earlier as a ‘split identity, patients seek to hold on to the healthy and autonomous self, the person they were before illness struck. However, reducing authenticity to autonomy may evoke an illusory image of the human being as invulnerable, as someone who should not be ill. Whatever the case, the roots of this romantic idea of authenticity can be found in contemporary narratives about constructing the self, where self-exploration, individual choice and control are seen as the basis for a valid identity (Ferrara 1998; Taylor 1992, 1989). From this perspective, the criterion for moral behaviour becomes decision making by a self-possessed and bounded individual who is capable of constructing his or her own character (Taylor 1989). Bearing in mind the progressive deterioration that characterises the end of life for advanced patients, a return to the idea of death as part of life, to the image of a vulnerable human being, may help patients achieve some form of acceptance during their final days.

Although, on a theoretical level, this view of authenticity may appear to be important and to have its echo in the medical decision-making process, it is not clear to what extent the concept is useful from the perspective of liberal philosophy. One of the reasons for this is that decision making is often governed by economic criteria that reduce the scope of choice to the social and economic value that is attributed to the person (notably less for the ill and older people), thus setting the bounds within which he or she may choose. From an ethical point of view, and linking the issue of authenticity to the idea of burden or ‘social death’, it is, as Rehmann-Sutter (2015) point out, “problematic if society (or a family) is structured in such a way that those who are no longer useful start feeling they are nothing but a burden. This is ethically problematic because it does not treat these people as beings with inherent moral worth” (Rehmann-Sutter, 2015: 169). Social death in the context of illness has to do with this (dis)attribution of the value of life and of the person. For some of the patients interviewed, being ill was synonymous with being useless (Mak and Elwyn 2005; Schroepfer 2006), and here again, one sees how what we take to be the basis of personal dignity can have numerous implications. If who you are, what you’re worth or the foundation of your dignity are decided by society, then it is easy, for example, to be reduced to your economic value. In fact, being an economic burden on the family was mentioned by some patients as a reason for their WTHD (Mak and Elwyn 2005). At all events, this kind of financial pressure will be most strongly felt in those countries where health care is not adequately funded or insured.

A further point to note is that medical discourse has been associated with bureaucratic procedures whose impact on the patient can be to heighten the sense of loss (Walter 1994). Viewing authenticity in terms of decision making (i.e. deciding within the limits of what is possible) rather than choice making (i.e. the desire for unlimited self-determination) might help patients to focus on who they are still able to be and what they are still able to do. There is clearly a tension here between the imposition of economic criteria, the expropriation of health and the idea of authenticity as something not subject to extrinsic rules, which ultimately renders it an empty concept.

Value of life

A topic of recent debate in the clinical context has been whether ‘meaning in life’ may serve a protective role (psychologically) in patients with advanced disease, and there is evidence to suggest that those individuals who express a WTHD experience a loss of meaning in life (Monforte-Royo et al. 2011). In our analysis of patient statements we observed that a loss of life’s value or meaning was the result of suffering for which there was no hope of a cure. It was also linked to a sense of diminished autonomy and control.

A recent systematic review of meaning-in-life interventions in the palliative care context concluded that patients can benefit from being given a space in which to reflect on areas or aspects that bring meaning to their life (Guerrero-Torrelles et al. 2016). We have seen in the present analysis that the value or meaning of life can be undermined when symptoms are not adequately managed (e.g. when a patient is in pain). This suggests that once the physical and psychological/emotional factors associated with a WTHD have been identified, interventions that can help patients rediscover a sense of dignity, of their own worth as a person, including in the eyes of others, may help them to live out their illness as a process of personal growth and a part of life.

CONCLUSIONS

Medicalisation appears to impact on the experience of patients who express a WTHD and to influence the way in which they conceive of their suffering, the end-of-life process and death. In a context characterised by suffering of this kind it is important that health professionals are able to understand patients’ assumptions and moral understandings about their situation so as to respond adequately to their needs and help them, as far as possible, to recover some of the social and intrinsic dignity they feel they have lost. An idea of authenticity based on decision making or self-agency may help to define a space in which advanced patients retain some room for manoeuvre, enabling them to experience their final days as a meaningful period of life.

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Competing Interests

The authors declare no competing interests.

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REFERENCES

Ariès, Philippe. 1975. *Western attitudes toward death: from the Middle Ages to the present* [Translated by Patricia M. Ranum]. Vol. 3. Baltimore: JHU Press.

Aristotle. 1995. *The Politics* [Translated by Ernest Barker]. New York: Oxford University Press.

Brody, B.A., 1989. *Suicide and euthanasia: Historical and contemporary themes.* Dordrecht: Kluwer Academic.

Callahan, Daniel. 1989. Can we return death to disease? *Hastings Center Report* 19: 4–6.

Chochinov, Harvey Max, T. Hack, S McClement, L. Kristjanson, and M. Harlos. 2002. Dignity in the terminally ill: A developing empirical model. *Social Science and Medicine* 54: 433–443.

Clark, David, 2002. Between hope and acceptance: the medicalisation of dying. *BMJ* 13: 905–907. doi:10.1136/bmj.324.7342.905

Conrad, Peter. 2008. *The medicalization of society: On the transformation of human conditions into treatable disorders*. Baltimore: JHU Press.

Coyle, Nessa, and Lois Sculco. 2004. Expressed desire for hastened death in seven patients living with advanced cancer: a phenomenologic inquiry. *Oncology Nursing Forum* 31, 699–709.

Dees, M. K., M. J. Vernooij-Dassen, W. J. Dekkers, K. C. Vissers, and C. van Weel. 2011. "Unbearable suffering": a qualitative study on the perspectives of patients who request assistance in dying. *Journal of Medical Ethics* 37: 727–734. doi:10.1136/jme.2011.045492

Ferrara, Alessandro. 1998. *Reflective authenticity. Rethinking the project of modernity.* London; New York: Routledge.

Gorer, Geoffrey. 1955. The pornography of death. *Encounter*: 49–52.

Guerrero-Torrelles, Mariona, Cristina Monforte-Royo, C, Andrea Rodríguez-Prat, Josep Porta-Sales, and Albert Balaguer. 2016. Understanding meaning in life interventions in advanced illness patients: A systematic review and realist synthesis. *Palliative Medicine.* doi*:* https: 10.1177/0269216316685235

Guo, Q., and C. S. Jacelon. 2014. An integrative review of dignity in end-of-life care. *Palliative Medicine* 28: 931–940. doi:10.1177/0269216314528399

Illich, Ivan. 1976. *Medical Nemesis: The expropiation of health*. London: Alder and Boyars.

Jors, K., S. Adami, C. Xander, C. Meffert, J. Gaertner, H. Bardenheuer, D. Buchheidt, R. Mayer-Steinacker, M. Viehrig, W. George, G. and Becker. 2014. Do the circumstances allow for a dignified death? *Cancer* 120: 3254–3260. doi:0.1002/cncr.28702

Kellehear, Allan. 2007. *A Social History of Dying.* Cambridge: Cambridge University Press.

Kelly, B., Burnett, P., Pelusi, D., Badger, S., Varghese, F., Robertson, M., 2002. Terminally ill cancer patients' wish to hasten death. Palliat. Med. 16, 339–345. doi:10.1191/ 0269216302pm538oa

Kemp, Peter, and J. D. Rendtorff. 2008. The Barcelona Declaration. Towards an Integrated Approach to Basic Ethical Principles *Synthesis Philosophica* 46: 239-251.

Lavery, James V., J. Boyle, B. M. Dickens, H. Maclean, and P. A. Singer. 2001. Origins of the desire for euthanasia and assisted suicide in people with HIV-1 or AIDS: A qualitative study. *Lancet* 358: 362–367.

Leung, D. 2007. Granting death with dignity: patient, family and professional perspectives. *International Journal of Palliative Nursing* 13: 170–175.

Mak, Y.Y.W., and G. Elwyn. 2005. Voices of the terminally ill: uncovering the meaning of desire for euthanasia. *Palliative Medicine* 19: 343–350.

Monforte-Royo, Cristina, Christian Villavicencio-Chávez, Joaquín Tomás-Sábado, and Albert Balaguer. 2011. The wish to hasten death: a review of clinical studies. *Psychooncology* 20: 795–804. doi:10.1002/pon.1839

Monforte-Royo, Cristina, Christian Villavicencio-Chávez, Joaquín Tomás-Sábado, Vinita Mahtani-Chugani, and Albert Balaguer. 2012. What lies behind the wish to hasten death? A systematic review and meta-ethnography from the perspective of patients. *PLoS One* 7, e37117. doi:10.1371/journal.pone.0037117

Morris, David B. 1991. *The culture of pain*. Oakland: University of California Press.

Nilmanat, K., C. Promnoi, T. Phungrassami, P. Chailungka, K. Tulathamkit, P. Noo-urai, and S. Phattaranavig. 2015. Moving Beyond Suffering: the Experiences of Thai Persons With Advanced Cancer. *Cancer Nursing* 38: 224–231. doi:10.1097/NCC.0000000000000169

Nissim, R., Gagliese, L., and G. Rodin. 2009. The desire for hastened death in individuals with advanced cancer: A longitudinal qualitative study. *Social Science and Medicine* 69: 165–171. doi:10.1016/j.socscimed.2009.04.021

Ohnsorge, Kathrin, Heike Gudat, and Cristoph Rehman-Sutter. 2014a. Intentions in wishes to die: analysis and a typology – A report of 30 qualitative case studies of terminally ill cancer patients in palliative care. *Psychooncology*. doi:10.1002/pon

Ohnsorge, Kathrin, Heike Gudat, and Cristoph Rehman-Sutter. 2014b. What a wish to die can mean: reasons, meanings and functions of wishes to die, reported from 30 qualitative case studies of terminally ill cancer patients in palliative care. *BMC Palliative Care* 13. doi:10.1186/1472-684X-13-38

Ohnsorge, Kathrin, H. Keller, G. Widdershoven, and C. Rehmann-Sutter. 2012. Ambivalence'at the end of life How to understand patients' wishes ethically. *Nursing Ethics* 19: 629–641. doi:10.1177/0969733011436206

Östlund, U., H. Brown, and B. Johnston. 2012. Dignity conserving care at end-of-life: a narrative review. *European Journal of Oncology Nursing* 16: 353–367. doi:10.1016/j.ejon.2011.07.010

Parens, Erik, 2013. On good and bad forms of medicalization. *Bioethics* 27: 28–35. doi:10.1111/j.1467-8519.2011.01885.x

Pearlman, Robert A., C. H. Hsu, A. L. Starks, A. L. Back, J. R. Gordon, A. J. Bharucha, B. A. Koenig, and M. P. Battin. 2005. Motivations for physician-assisted suicide. *Journal of General Internal Medicine* 20: 234–239. doi:10.1111/j.1525-1497.2005.40225.x

Pestinger, Martina, S. Stiel, F. Elsner, G. Widdershoven, R. Voltz, F. Nauck, and L. Radbruch. 2015. The desire to hasten death: Using Grounded Theory for a better understanding "When perception of time tends to be a slippery slope." *Palliative Medicine* 29: 711–719. doi:10.1177/0269216315577748

Pullman, Darryl. 1996. Dying with Dignity and the Death of Dignity. *Health Law Journal* 4: 197–219.

Quill, Timothy E., and M. P. Battin. 2004. *Physician-assisted dying: the case for palliative care and patient choice*. Baltimore: The Johns Hopkins University Press.

Rehman-Sutter, Cristoph, 2015. End-of-life ethics from the perspectives of patients' wishes. In *The Patient's Wish to Die. Research, Ethics, and Palliative Care,* eds. C. Rehman-Sutter, C., H. Gudat, H., and K. Ohnsorge. Oxford: Oxford University press.

Rendtorff, J.D., 2002. Basic ethical principles in European bioethics and biolaw: autonomy, dignity, integrity and vulnerability. Towards a foundation of bioethics and biolaw. *Med. Health Care. Philos* 5: 235–244. doi:10.1023/A:1021132602330

Rodríguez-Prat, Andrea, Cristina Monforte-Royo, Josep Porta-Sales, Xavier Escribano, and Albert Balaguer. 2016. Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography. *PLoS One* 11, e0151435. doi:doi: 10.1371/journal.pone.0151435

Rodríguez-Prat, Andrea, Albert Balaguer, Andrew Booth, Cristina Monforte-Royo. 2017. Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography.

Schroepfer, T. A., 2006. Mind Frames Towards Dying and Factors Motivating Their Adoption by Terminally Ill Elders. *Journal of Gerontology* 61: 129–140.

Steinhauser, K.E., N. A. Christakis, E. C. Clipp, M. McNeilly, L. McIntyre, and J. A. Tulsky. 2000. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 284: 2476–2482.

Stiel, Stephanie, M. Pestinger, A. Moser, G. Widdershoven, U. Lüke, G. Meyer, R.Voltz, F. Nauck, and L. Radbruch. 2010. The Use of Grounded Theory in Palliative Care: Methodological Challenges and Strategies. *Palliative Medicine* 13: 997–1003. doi:10.1089/jpm.2010.0050

Street, A.F., and D. W. Kissane. 2001. Constructions of dignity in end-of-life care. *Journal of Palliative Care* 17: 93–101.

Sulmasy, Daniel P. 2005. Death, Dignity, and the Theory of Value. *Ethical Perspec*t 9: 103–130. doi:10.2143/EP.9.2.503850

Taylor, Charles. 1992. *The ethics of authenticity*. Cambridge: Harvard University Press.

Taylor, C. 1989. *Sources of the self: The making of the modern identity.* Cambridge: Harvard University Press.

United Nations. 1948. Universal Declaration of Human Rights. http://www.un.org/es/documents/udhr/index_print.shtml. Accessed 14 October 2016.

van Wijngaarden, E., C. Leget, and A. Goossensen. 2016. Disconnectedness from the here-and-now: a phenomenological perspective as a counteract on the medicalisation of death wishes in elderly people. *Medicine, Health Care and Philosophy* 19: 265–273. doi:10.1007/s11019-016-9687-4

Varga, Somogy, and Charles Guignon. 2016. Authenticity. Stanford Encycl. Philos. http://plato.stanford.edu/archives/sum2016/entries/authenticity. Accessed 15 November 2016.

Walker, Margaret Urban. 2007. *Moral Understandings: A Feminist Study in Ethics.* New York: Oxford University Press.

Walter, T. 1994. *The revival of death*. London; New York: Routledge.

White, M., and D. Callahan. 2000. Oregon's first year: The medicalization of control. *Psychology Public Policy, and Law* 6: 331–341. doi:10.1037//1076-8971.6.2.331

Quinto artículo: Ethical challenges for an understanding of suffering: Voluntary stopping of eating and drinking and the wish to hasten death in advanced patients

Presentación:

Recientemente Bolt et al. (2015) llevaron a cabo un estudio retrospectivo sobre el VSED en el que citan la revisión sistemática de estudios cualitativos sobre pacientes con enfermedades avanzadas que habían expresado deseo de adelantar la muerte (Monforte-Royo et al., 2012), realizada por nuestro grupo. En ella se describió el DAM como un fenómeno complejo, reactivo a la presencia de un sufrimiento multidimensional, que va en la línea de llevar a cabo "investigación cualitativa para aumentar nuestra comprensión de los motivos de los pacientes que conducen a adelantar la muerte a través del VSED", tal y como Bolt et al. (2015) subrayan en su estudio.

A la luz del estudio de Bolt et al. (2015) en *Annals of Family Medicine,* y de la réplica que Quill (2015) y de Jansen (2015) hacen a ese estudio, pensamos que podía ser una interesante aportación el profundizar en el fenómeno complejo del VSED apoyándonos en los resultados obtenidos por nuestro equipo de investigación sobre el DAM.

Esta reflexión, pensamos que podía aportar una nueva perspectiva a la comprensión de este fenómeno y ser de interés para los profesionales de la salud que se enfrentan a él.

Ethical challenges for an understanding of suffering: Voluntary stopping of eating and drinking and the wish to hasten death in advanced patients

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Abstract

Some persons with advanced disease but no significant cognitive impairments consciously decide to stop taking food and fluids orally, even though they remain physically able to do so. The question is to what extent voluntarily stopping eating and drinking (VSED) may be considered an expression of a wish to hasten death, understood as a reaction to suffering due to a life-threatening illness, in the sense that the latter has been recently defined. Here, we analyse the data reported in some studies in relation to primary care patients who died as a result of VSED and examine their results in light of the qualitative findings of patients that expressed a wish to die. In our view, VSED is consistent with such a wish, since in these patients it is underpinned by one or more kinds of suffering. Therefore, prior to interpreting this act as a deliberate expression of personal autonomy, it is important to explore all possible areas of suffering, including physical symptoms (either present or foreseen), psychological distress, existential suffering and social aspects. Failure to do will mean that we run the risk of abandoning a fellow human being to his or her suffering.

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Voluntarily stopping eating and drinking" (VSED) is a topic that raises challenging ethical questions. VSED defined as "an action of a competent, capacitated person, who voluntarily and deliberately chooses to stop eating and drinking with the primary intention to hasten death because unacceptable suffering persists"[1,2] leads to crucial questions about clinical ethics and clinical practice: What is the quality of life of the patients who prefer to die than to carry on living? What is the good care to provide to these patients and what is the good for them? What factors contribute to some patients wanting to die? Should this be understood as an unequivocal case of the WTHD, as a request to end their life?

In a recent study carried out by Bolt et al.[1] in the Netherlands, the role and involvement of family physicians when confronted with patients who accelerate their death by VSED was analysed. The data from this study[1] suggest that VSED is a decision taken by adult or older patients with severe disease, short life expectancy, and dependency on others for everyday care. Importantly, these people are physically able to take in food and fluids orally, but they are consciously unwilling to do so.

The statements made in this article led us to reflect on whether VSED can properly be considered a particular case of the WTHD and, if it is the case, what the implication would be for clinical practice. Our reflection is based on the systematic review and synthesis of qualitative studies (meta-ethnography) on the meaning of the WTHD in patients with advanced disease carried out by our group[3] as well as on a recent consensus definition of the WTHD in which we participated. This proposal understands that "the WTHD is a reaction to suffering, in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate his or her death”.[4]

Our goal is to contribute to the understanding of patients who voluntarily stop eating and drinking, and, therefore, to help improve the practice of physicians who are responsible for their care. In what follows, we will also try to compare the data regarding the VSED and the results derived from our meta-ethnography[3] which highlighted that any expression of the WTHD was underpinned by suffering. This suffering was seen as a response to physical-psychological-spiritual-existential impairment.

In the study of Bolt et al.,[1] different levels of suffering are likewise apparent among the patients who voluntary chose to die by VSED. The most common patient motives for hastening death reported by family physicians were somatic (79%), existential (77%), and dependence-related (58%). Other reasons mentioned included loss of sense of dignity and loss of self, social factors, and psychiatric suffering. These variables are clearly consistent with the idea of the WTHD as a reaction to physical, psychological, and/or spiritual suffering.

One conclusion to be drawn from this Dutch study[1] is that patients with severe disease may regard VSED as a way of ending their suffering and of exerting some control over their life. Similarly, the patients considered by our meta-ethnography did not regard death as an end in itself but, rather, as a way of escaping from overwhelming suffering.

Furthermore, some patients experienced both a wish to die and a wish to go on living. This paradox is also observed among patients who chose to die by VSED,[1] since the dying phase is then both prolonged and potentially reversible. This reversibility would appear to reflect two aspects that emerged in our study,[3] namely the possibility of controlling when and how one dies ("to have an ace up one's sleeve just in case") and the "desire to live but not in this way". Again, we see the idea that death was not always what the patients wished for but it can also mean to end a life that apart from the context of their illness would have been wanted.

Some of the points made by Quill[5] regarding VSED are also consistent with the findings of our meta-ethnography.[3] For example, he mentions the idea of AS as a "last resort" when faced with extreme suffering. The proximity of inevitable death can lead some persons to experience an intense need for control, and in such cases, taking decisions about how one lives or dies may become a good control strategy that reduces emotional distress or even fosters an improved sense of wellbeing. In this context, the more extreme the suffering the greater may be the need for control, and thus it becomes more likely that a person will take such decisions. For a person in such a situation, being able to decide for oneself how and when one dies may be experienced as a form of self-determination, as preserving what little is left of the life he/she once had.

A similar paradox is present in other observation made by Quill,[5] since he suggests that for patients like the one he describes AS may have more to do with self-preservation than self-destruction. However, it is worth remembering that a common experience reported in studies of advanced patients who request AS[6–8] is a "loss of the self", the sense that one's own essence or identity is disintegrating ("I'm no longer the person I was before the illness"). Within this framework, therefore, the WTHD would correspond to a manifestation of the desire to flee from a reality dominated by suffering, and thus it is perhaps accepts the idea of destructing a disintegrating self rather than the wish to assert one's own individuality. In many cases, as stated above, the idea of a loss of self is associated with a perceived loss of sense of dignity and meaning in life. This raises the question as to what extent the decision — based on personal autonomy — to end one's life can be regarded as an act of self-preservation.

Having compared the findings reported in the Dutch study[1] with those of the meta-ethnography[3] and the operational consensus definition of the WTHD[4] we confirm that VSED can be regarded as a particular expression of the WTHD. Hence, like the WTHD, the act of VSED should be understood as being underpinned by one or more kinds of suffering, the causes of which would need, in clinical practice, to be identified and, if possible, addressed in some way. Although, in the Dutch study[1] only 13% of the 99 patients who died by VSED were said to have reported depressive symptoms, studies that have analyzed predictors of the WTHD in advanced patients have found that depression is one of the strongest predictors.[9,10] Due to the retrospective nature of the study,[1] however, it is not known whether any attempts were made by family physicians to rule out this factor or, in the event that it was present, to provide treatment. The evidence to date[10,11] suggests that proactive intervention in relation to the WTHD may be a crucial step in alleviating the suffering experienced by many patients and in widening the focus beyond the desire to die, which has also been described as a "cry for help".[3,12,13]

Jansen[14] notes that VSED is described in the literature as a treatment option rather than as an activity undertaken by a patient on his/her own. Viewed in this way, namely as an option that can be potentially supported by the clinician, its ethical consideration would be very similar to that of AS. In this context, supporters of VSED have proposed that the practice be brought under the umbrella of standard care, whereas those who oppose it fear that this would lead physicians to regard it as just another viable option for those patients who, due to their suffering, wish to put an end to their life. Therefore, in terms of the ethical challenge posed by VSED, there is a need, as with the WTHD, to do all we can to understand what lies behind this complex phenomenon. For if ethics implies an inquiry into what we are capable of doing or not doing, and into how the greater good may be achieved, then we need to explore further what it means when someone expresses the wish to die. Thus, in every case it should be determined whether the WTHD is either part of a clinical mental condition (depression or psychological impairments), an expression of wish to end a process of disintegration, etc. Even if such conditions are ruled out, it would be wise, prior to interpreting this act as a deliberate expression of personal autonomy, to explore all possible areas of suffering, including physical symptoms (either present or foreseen), psychological distress, existential suffering, and social aspects. Otherwise, respecting the autonomous desire of the patient could be at the detriment of providing good care for and determining the good of the patient in all those cases in which there is a treatable condition. Failure to do so would mean that we run the serious risk, both as health professionals and as human individuals, of abandoning a fellow human being to a fate in which suffering pervades.

References

1. Bolt EE, Hagens M, Willems D, Onwuteaka-Philipsen BD. Primary care patients hastening death by voluntarily stopping eating and drinking. *Ann Fam Med* 2015;13(5):421-428. doi:10.1370/afm.1814.

2. Ivanović N, Büche D, Fringer A. Voluntary stopping of eating and drinking at the end of life - a “systematic search and review” giving insight into an option of hastening death in capacitated adults at the end of life. *BMC Palliat Care* 2014;13(1). doi:10.1186/1472-684X-13-1.

3. Monforte-Royo C, Villavicencio-Chávez C, Tomás-Sábado J, Mahtani-Chugani V, Balaguer A. What lies behind the wish to hasten death? A systematic review and meta-ethnography from the perspective of patients. *PLoS One* 2012;7(5):e37117. doi:10.1371/journal.pone.0037117.

4. Balaguer A, Monforte-Royo C, Porta-Sales J, et al. An international consensus definition of the wish to hasten death and its related factors. *PLoS One* 2016;11(1):1-14. doi:10.1371/journal.pone.0146184.

5. Quill TE. Voluntary stopping of eating and drinking (VSED), physician-assisted death (PAD), or neither in the last stage of life? Both should be available as a last resort. *Ann Fam Med* 2015;13(5):408-409. doi:10.1370/afm.1850.

6. Lavery J V., 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(9279):362-367.

7. Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: A developing empirical model. *Soc Sci Med* 2002;54(3):433-443.

8. Pearlman RA, Hsu C, Starks H, et al. Motivations for physician-assisted suicide. *J Gen Intern Med* 2005;20(3):234-239. doi:10.1111/j.1525-1497.2005.40225.x.

9. Chochinov HM, Wilson KG, M E, N M. Desire for death in the terminally ill. *Am J Psychiatry* 1995;152:1185-1191.

10. Villavicencio-Chávez C, Monforte-Royo C, Tomás-Sábado J, Maier MA, Porta-Sales J, Balaguer A. Physical and psychological factors and the wish to hasten death in advanced cancer patients. *Psychooncology* 2014;23:1125-1132. doi:10.1002/pon.3536.

11. Breitbart W, Rosenfeld B, Pessin H, et al. Depression, Hopelessness, and Desire for Hastened Death in Terminally Ill Patients With Cancer. *J Am Med Assoc* 2000;284(22):2907-2911.

12. Coyle N, Sculco L. Expressed desire for hastened death in seven patients living with advanced cancer: a phenomenologic inquiry. *Oncol Nurs Forum* 2004;31(4):699-709.

13. 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(2):165-171. doi:10.1016/j.socscimed.2009.04.021.

14. Jansen LA. Voluntary Stopping of Eating and Drinking (VSED), Physician-Assisted Suicide (PAS), or Neither in the Last Stage of Life? PAS: No; VSED: It Depends. *Ann Fam Med* 2015;13:410-411.

Capítulo 11. Discusión

Aunque los resultados de cada estudio han sido discutidos en sus correspondientes artículos, en este apartado se discutirán los resultados a la luz de las preguntas de investigación previamente planteadas.

Preguntas de investigación:

1. ¿Cómo es experimentada la relación entre dignidad percibida y autonomía, control o autodeterminación en los pacientes con enfermedades avanzadas?

En el proceso de codificación y categorización de las narraciones de los participantes en los estudios primarios se identificaron tres temas que describían las distintas mediaciones entre dignidad y autonomía: la pérdida de funcionalidad física como mediador de la dignidad, la dignidad como identidad y la autonomía como factor determinante de la percepción de dignidad.

El primer tema emergido, la percepción de dignidad mediada por la pérdida de funcionalidad, es una constante en estudios sobre la vivencia de la enfermedad. En el contexto de final de vida, tanto en los estudios focalizados en la percepción de la dignidad y control, DAM o actitudes vinculadas a la eutanasia y suicidio asistido, fue un punto de partida inevitable, puesto que la vivencia de la dignidad está condicionada por la enfermedad. En estudios como el de Chochinov et al. (2002), Volker (2004b), Pearlman et al. (2005), Brown et al. (2011) y Ho et al. (2013), la pérdida de funcionalidad fue expresada en términos de los problemas que derivan de la enfermedad en sí misma y que repercuten en la percepción de la propia dignidad. En otros estudios, la pérdida de funcionalidad fue expresada directamente como ‘desintegración’ (Lavery et al., 2001) ‘pérdida del yo o e de la esencia’ (Lavery et al., 2001; Pearlman et al., 2005) y ‘percepción del sufrimiento del yo’ (Mak y Elwyn, 2005).

El segundo tema identificado, la dignidad como identidad, se definió a partir de la vivencia de la percepción de la propia identidad también en relación a los demás. Numerosos autores han destacado el impacto de la transformación física en la consideración personal (Aujoulat, Marcolongo, Bonadiman y Deccache, 2008; Charmaz, 1983, 1995; Enes, 2003; Kleinman, 1988; Paterson, 2001; Street y Kissane, 2001). Street y Kissane (2001) establecieron que la ‘dignidad es encarnada’ puesto que las personas se conocen y son conocidas en su corporalidad. Es por esto que la vivencia de la enfermedad puede suponer una división entre quién se considera la persona y el cuerpo que ya no reconoce como suyo porque está “alterado” (Charmaz, 1995). Franklin et al. (2006) llamaron a este hecho “el cuerpo irreconocible” y Kristeva “el cuerpo abyecto” (citado en Street y Kissane, 2001).

Por otro lado, la reflexión en torno a la identidad está asociada a ciertas emociones de valoración personal como la autoestima (Chochinov et al., 2002; Enes, 2003; Kade, 2000; Lavery et al., 2001; Pearlman et al., 2005; Volker et al., 2004b). Otra emoción común es el miedo ante el “perderse a uno mismo”: dejar de ser la persona que se había sido y defraudar a los demás; o vergüenza ante la falta de privacidad y la pérdida de la intimidad que la necesidad de ayuda para la realización de actividades básicas conlleva, o de falta de dominio personal causado por la enfermedad.

Paralelamente, la consideración personal no puede separarse de cómo la persona se siente mirada y tratada por los demás. Chochinov et al. (2002) –y los estudios que han seguido su modelo de dignidad– identificaron como uno de los temas principales el ‘Inventario de Dignidad Social’ que tiene que ver con la influencia de las relaciones sociales en la vivencia de la dignidad. En estudios sobre el DAM, eutanasia o suicidio asistido, son constantes las expresiones de miedo a hacer sufrir a los demás y de querer poner fin a la vida como un gesto altruista (Compassion & Choices, 2008; Coyle y Sculco, 2004). La categoría “ser una carga para los demás” también ha sido destacada en diversos estudios; y en ocasiones, esta realidad se ha visto reforzada por el miedo a verse vulnerables e inútiles por sus seres queridos. De nuevo estas ideas tendrían que ver con la percpeción de pérdida de la propia identidad señalado arriba. Por otro lado, las situaciones de final de vida han sido entendidas como una ocasión para reforzar ‘la conexión y sentido de pertenencia’ con los seres queridos (Enes, 2003; Mak y Elwyn, 2005; Pearlman et al., 2005). Este aspecto también ha sido reconocido en una reciente revisión sistemática de intervenciones de sentido de la vida realizada por nuestro grupo (Guerrero-Torrelles et al., 2017).

El último tema que emergió en esta revisión sistemática fue el de la autonomía como un factor determinante de la dignidad percibida. En la literatura sobre el DAM, eutanasia y suicidio asistido es recurrente la defensa a favor de la ‘Muerte con Dignidad’ bajo el supuesto de que la dignidad de la persona depende de que mantenga su autonomía y control. En la primera meta-etnografía publicada sobre el DAM (Monforte-Royo et al., 2012) se identificó que este deseo de adelantar la muerte surgió “como una forma de control sobre la propia vida”. En el presente estudio, el subtema ‘deseo de control sobre el proceso de morir’ tendría que ver con este deseo de mantener cierto tipo de control sobre las distintas circunstancias, que no necesariamente significaría llevar a cabo alguna acción para morir. Sin embargo, el segundo subtema, “deseo de autodeterminación”, sí que estaría directamente relacionada con el deseo y voluntad explícitos de poner fin a la propia vida.

En un nivel interpretativo superior se vio que estos temas no podían entenderse de forma aislada sino entrelazados entre sí. Tras el análisis de los estudios en los que se relacionaba dignidad y autonomía puede observarse que todas las vivencias de los participantes estuvieron penetradas por la vivencia de la enfermedad, por la influencia del contexto social y por el impacto en la identidad personal (modelo explicativo). Por ejemplo, se encontró que la pérdida de funcionalidad física vinculada a la percepción de dependencia es el mayor mediador en la pérdida de sentido de dignidad. En este caso, no podría entenderse la dependencia fuera del impacto de la enfermedad, la nueva relación establecida con el entorno inmediato y la construcción de una nueva identidad.

2. ¿El sentido de dignidad personal (cómo las personas se atribuyen o no dignidad) puede influir en la vivencia de su enfermedad y en su toma de decisiones?

Partiendo de ete modelo explicativo se observaron dos posiciones extremas: en los casos donde los pacientes subrayaron la conciencia de un sentido intrínseco de la dignidad se mantuvo un sentido positivo de la dignidad ante la presencia de la enfermedad. Por el contrario, los pacientes que fundamentaron su dignidad en valores como la autonomía, la capacidad de control o la calidad de vida, su percepción sobre la misma se vio mermada.

Uno de los temas clave que emerge del presente análisis es la respuesta del deseo de control sobre el proceso final de vida en quienes fundamentan la dignidad en la autonomía. Si bien es verdad que existe cierta confrontación sobre las motivaciones de quienes solicitan la eutanasia o el suicidio asistido, en esta síntesis se ha hecho más evidente cómo las personas con un fuerte carácter independiente y “controladoras” (como muchas veces se las denomina en el argot biomédico), en circunstancias de falta de control sobre el dolor, incapacidad de disfrutar de la vida ordinaria o de ser una carga para los demás, pueden tener más tendencia a desear adelantar la muerte.

3. ¿Qué aporta la fenomenología de la corporalidad y de la enfermedad a los estudios cualitativos publicados en los que se establece la relación entre la dignidad percibida y la autonomía?

Tras el análisis efectuado puede entreverse que tanto la noción de dignidad como de cuerpo vivido refieren a la persona como un todo. Desde la fenomenología, el cuerpo no es visto solo como un objeto capaz de ciertos mecanismos definidos en términos anatómicos o fisiológicos sino también como un cuerpo encarnado, vivido, sujeto de interpretaciones, experiencias, emociones, deseos, situado en un mundo y en una cultura determinada. En los estudios cualitativos sobre dignidad puede observarse que cualquier cambio en el “mundo” particular de cada paciente puede afectar a su percepción de dignidad. Del mismo modo, la vida de cada persona se desarrolla siempre desde el cuerpo vivido por lo que cualquier cambio puede repercutir en su experiencia del mundo y, de forma especial, la enfermedad desequilibra radicalmente la estructura yo-cuerpo-mundo-otros. Es por eso que la perspectiva cualitativa puede aportar muchas luces a la práctica clínica: dar voz a la experiencia de los pacientes, profundizar en la comprensión del mundo del otro, comprender el cuerpo desde un punto de vista más completo (el cuerpo como realidad física, como campo de localización de sensaciones, como centro de acción, como portador del libre movimiento, como obstáculo, etc.).

En la práctica clínica, las consecuencias de considerar a la persona como sujeto encarnado (como un todo) son innumerables. La misma Toombs describe algunas implicaciones: comunicarse efectivamente con los pacientes, comprender los síntomas físicos, responder a las necesidades de los pacientes, reconocer y aliviar el sufrimiento y el dolor (en sentido amplio), responder a las características vivenciales de la enfermedad, y atender de forma personalizada (teniendo en cuenta que cada persona es única y vive la realidad de una forma única) a los problemas particulares de quien pide ayuda (Toombs, 1992).

4. ¿Cuál es la experiencia del deseo de adelantar la muerte expresado por pacientes con enfermedades avanzadas?

La actualización de la revisión sistemática y meta-etnografía de estudios cualitativos sobre el DAM ha revelado que, en pacientes avanzados, es un fenómeno que se produce en un contexto de sufrimiento, identificándose éste como un tema dominante, como un denominador común presente en los demás subtemas. De hecho, los únicos dos estudios cualitativos incluidos en esta revisión que no tenían como objetivo principal explorar el DAM, estaban dirigidos a explorar el sufrimiento (Dees et al., 2011; Nilmanat et al., 2015).

El segundo tema, razones, hizo referencia al DAM como respuesta a factores físicos, psicológicos y emocionales, sociales, existenciales y espirituales conectados con una fuerte experiencia de sufrimiento y de pérdida del yo. El dolor en algunos estudios emergió como factor catalizador en el desarrollo del DAM. Algunos de los entrevistados percibieron este dolor como el factor sin el cual no desearían morir. Aunque el dolor es uno de los elementos que durante décadas se postuló como ‘causa’ primaria de DAM, desde finales de los años noventa, la mayor parte de los estudios no lo identifican como factor primordial en el desarrollo del DAM (Monforte-Royo et al., 2011). En cambio, gran parte de los estudios han encontrado una estrecha relación entre un mayor deterioro funcional, dependencia, pérdida de autonomía y DAM. Por ejemplo, un estudio reciente (Guerrero-Torrelles et al., 2017) realizado por nuestro grupo, propone un modelo en el que pérdida de sentido de la vida y depresión median la relación entre discapacidad física y DAM. No obstante, esta síntesis realizada como parte de esta tesis destaca el dolor físico como elemento clave en la emergencia del DAM. Esta disparidad en los resultados podría deberse a que desde un punto de vista vivencial (cualitativo), la sintomatología física y el estatus funcional, el sufrimiento psico-existencial, la nueva relación que se establece con el entorno social inmediato, etc., son vividos como una realidad inseparable. El dolor físico o la pérdida de funcionalidad pueden llevar a la desesperanza, impactar en la identidad personal y hacer que disminuya el sentido de la vida. En este sentido, la noción de ‘dolor total’ de Cicely Saunders (1965) puede ayudar a ilustrar esta idea de dolor o sufrimiento multidimensional que afecta a toda la persona.

Asimismo, aunque los autores de los artículos incluidos distingan entre las diferentes razones o motivaciones que contribuyen a la emergencia del DAM, de hecho, están entrelazadas y, en algunos casos resulta difícil de diferenciar las distintas dimensiones (física, psicológica, emocional, social y existencial) desde la experiencia. Por ejemplo, aunque sentido de la vida o pérdida del sentido de la dingnidad muchas veces se encuadran en la esfera de lo psico-emocional-existencial, en nuestro análisis definimos estas categorías en el marco de pérdida del yo, que fue definido desde la inclusión de todas las dimensiones de la persona.

Nuestra síntesis identificó como tercer tema “significados” (*meanings)*. Identificar que el DAM tiene unos significados que no son propiamente desear la muerte (como fin en sí mismo), es crucial para entender la naturaleza compleja y dinámica del DAM. En algunos estudios, por ejemplo, se ha señalado que el DAM fluctúa en el tiempo (Chochinov et al., 1999; Galushko et al., 2015) y en ocasiones puede ser ambivalente (las personas pueden tener deseos contradictorios) (Coyle y Sculco, 2004; Mak y Elwyn, 2005; Ohnsorge et al., 2012). En este sentido, atender a los significados atribuidos a este DAM es determinante para entender mejor al paciente que lo expresa. Asimismo, es importante destacar que aunque los significados identificados en esta actualización emergieron de los verbatims de los participantes, podrían existir distintos significados en función de los valores de los participantes (Ohnsorge et al., 2012; Rehman-Sutter, 2015). Esto implica la necesidad de conocer el trasfondo cultural y biográfico de los pacientes que expresan el DAM a la hora de entender qué quieren decir cuando lo verbalizan.

El cuarto tema, “funciones” emergió como respuesta a qué finalidad tenía el DAM para cada paciente (para qué). Se identificaron dos subtemas: el DAM como un medio para comunicarse y el DAM como una forma de control. En todos los estudios puede observarse que el DAM sirvió para expresar ‘algo más’ que el deseo de morir. En casos puntuales, la function comunicativa del DAM se hizo explícita como medio para fortalecer los lazos familiares y resaltar la importancia del cuidado y presencia de los seres queridos para el paciente. Incluir a los familiares en la toma de decisiones fue una forma de hacerlos responsables de su situación, de asegurar su presencia y, en parte, de poner los medios para evitar el abandono. En algún caso, la alusión al DAM fue utilizada para manipular a los familiares, personas cercanas y profesionales, para ser mejor atendidos o conseguir algún tipo de provecho personal. En la mayoría, el DAM fue la expresión (comunicación) del sufrimiento que presentaban los pacientes (Coyle y Sculco, 2004).

El “DAM como una forma de control”, si bien ya estaba presente en la meta-etnografía original, en esta actualización fue analizado poniendo atención a la situación legal de los países donde están despenalizadas la eutanasia o el suicidio asistido. De los catorce estudios incluidos, en seis (Dees et al., 2011; Ohnsorge et al., 2012; Ohnsorge, Gudat y Rehmann-Sutter, 2014a, 2014b; Pearlman et al., 2005; Schroepfer, 2006) se aludió explícitamente a médicos o institutions que podían dar soporte a las personas interesadas en suicidio asistido o eutanasia. Contactar con organizaciones de derecho a morir, fue visto como el “último control” que la persona podía tener en el marco de una enfermedad terminal que condicionaba su vida. Algunos de los pacientes que manifestaron este deseo de control acabaron muriendo por la administración de estas lethal drugs (Dees et al., 2011; Pearlman et al., 2005). En los países donde no son legales, se hizo alusión a planes hipotéticos en los que se barajaba la posibilidad del suicidio. De nuevo, el deseo de poner fin al sufrimiento fue el motivo principal que condujo a estos pacientes a desear este control sobre el proceso de final de vida.

El último tema, “experencia vivida de la temporalidad respecto a la muerte y al morir” emergió como una dimensión que contextualizaba las expresiones de los pacientes en un marco temporal. La vivencia del tiempo, en los estudios incluidos, solo apareció de forma explícita –esto es como tema identificado en el análisis de los datos- en el estudio de Pestinger et al. (2015). Sin embargo, en los demás estudios, los pacientes, al hablar de la vivencia del deterioro progresivo, del miedo, de la angustia, de la desesperanza, de la pérdida de control, etc., hicieron referencias implícitas a su situación en relación al pasado, presente y futuro. Asimismo, es interesante observar que el DAM en este marco temporal solo se ha destacado desde los estudios cualitativos. Profundizar en el contexto vivencial sin duda puede ayudar a entender mejor cómo es la experiencia de estos pacientes y salir al paso de sus incertidumbres y preocupaciones.

5. ¿Los distintos contextos legales pueden influir en la toma de deciones de los pacientes que expresan el deseo de adelantar la muerte?

A partir de los resultados de esta actalización de estudios cualitativos sobre el DAM se observa que la eutanasia y el suicidio asistido son los medios a través de los cuales se puede encauzar el deseo de morir. Es decir, los pacientes que deseaban morir tenían los recursos necesarios para dar cauce a sus deseos. Hasta el momento no hay ningún estudio que aporte evidencia sobre si la despenalización de la eutanasia o suicidio asistido, aumenta la tasa de mortalidad de forma indiscriminada o no. Por un lado, defensores del ‘Derecho a morir’ sostienen que finalmente las personas que mueren por estas prácticas son una minoría respecto a la población diana y que en todo caso, estas leyes, protegen a los individuos de un proceso de final de vida doloroso e ‘indigno’ (Battin, 1995; Quill, 1991). Por otro lado, sus detractores plantean que con estas leyes se propicia la génesis de una pendiente resbaladiza que puede afectar especialmente a poblaciones vulnerables (especialmente a ancianos y a enfermos terminales). Considerando los hallazgos de nuestro análisis, y teniendo en cuenta las limitaciones de esta valoración por el tamaño de la muestra y el acceso indirecto de las fuentes, podría decirse que el hecho de tener prácticas que posibilitan a los pacientes darse muerte hace que más pacientes acaben dándose muerte que lo que lo harían los pacientes en países donde no están despenalizadas la eutanasia y el suicidio asistido. En los estudios de Ohnsorge, Gudat y Rehmann-Sutter (2014a; 2014b), por ejemplo, aparecen numerosas referencias a las organizaciones de derecho a morir. En las entrevistas, algunos de los pacientes mencionaron de forma explícita cómo habían contactado con éstas y, en algunos casos, los pacientes acabaron falleciendo por la ingestión de las drogas letales. Sin embargo, en los países donde estas prácticas no son legales, el suicidio solo se planteó como un plan hipotético. De los pacientes donde estas prácticas están despenalizadas, finalmente solo un paciente acabó muriendo por suicidio.

6. ¿Qué valores y presupuestos morales pueden identificarse en las citas de los estudios cualitativos sobre el deseo de adelantar la muerte expresado por los pacientes, profesioanles de la salud y familiares considerando como marco contextual “la medicalización”?

Tras una lectura atenta de todas los verbatims de los estudios cualitativos sobre el DAM, se identificó que la mayoría reflejaban valores y presupuestos que encajaban bien con el concepto de la medicalización.

Un dato relevante para este análisis es que los participantes de los estudios sobre el DAM, en muchas muchas de los verbatims (41 de 122), describieron su enfermedad, su experiencia del sufrimiento, de la anticipación de la muerte en base a afirmaciones que traían a colación imágenes de que no siempre se basaban en la realidad que vivían estos pacientes. Por ejemplo, en muchas de estos verbatims se reflejó la anticipación de lo que les ocurriría en un futuro más que lo que sucedía en el presente. Si bien es verdad que algunas de estas proyecciones estuvieron condicionadas por las propias vivencias pasadas o por las de gente cercana que había vivido situaciones similares, en otros casos, estas representaciones fueron el resultado de esta “rica imaginación” (Pestinger et al., 2015) sobre la muerte y el morir inseparable del imaginario del contexto cultural de las sociedades occidentales en las que se sitúan los pacientes. Las sociedades en función de los valores e ideales predominantes, configuran una representación sobre algunas realidades y en este caso sobre la enfermedad, el sufrimiento, la muerte, etc. De este modo, como testigos de su tiempo, los participantes reflejaron en su forma de verbalizar la vivencia de la enfermedad, no solo su experiencia entendida como algo meramente individual sino también aquellas imágenes que se han extendido en las sociedades (post)modernas occidentales.

Como hemos visto desde la experiencia de los pacientes es común la referencia a la dignidad dinámica como una cualidad vivida de forma subjetiva y dependiente de las circunstancias. Sin embargo, desde la experiencia personal, la referencia a un sentido de dignidad intrínseco es prácticamente inexistente. A pesar de esto, en algunas de las citas puede observarse cómo al hablar sobre esta dignidad dinámica se presupuso una dignidad intínseca que no había sido respetada. La actitud moderna de la privación de la muerte puede conducir a una defunción anónima, entendida como algo que le sucede a un individuo desinformado, paciente, sin control sobre su proceso final. Esta muerte hospitalizada podría ser una amenaza para la persona al no estar a la altura del respeto ni dignidad que merece. Un estudio reciente plantea con su título una pregunta interesante: '*Do the circumstances allow for a dignified death?*' ['¿Permiten las circunstancias una muerte digna?'] (Jors et al., 2014). Tal y como hemos visto a través de algunos verbatims, frecuentemente, el entorno que rodea a la persona al final de la vida no es el que más favorece que se sienta cuidada y atendida como merecería.

En este sentido, Charles Taylor (1992), entre otros, ha señalado la importancia del reconocimiento mutuo –basado en una idea de dignidad universal e igualitaria en los derechos– como aquello que configura la propia identidad. En el ámbito clínico, este reconocimiento podría proteger la dignidad de personas en situaciones vulnerables a través del cuidado (tú cuidas al otro porque lo respetas y lo reconoces como persona digna). De esta forma, la dignidad personal sería protegida de una forma más profunda al reconocer a la persona como ser humano (por lo tanto, por definición como alguien digno) que al atribuir a la persona ciertas características por las que nos pensamos a nosotros mismos merecedores o no merecedores del respeto de quienes nos rodean" (Taylor 1992).

Desde un punto de vista normativo, podría ser difícil acordar cuáles podrían ser las consecuencias prácticas de poseer una dignidad intrínseca, pero reconocer a otro ser humano como ser humano es necesario para respetar a las personas y protegerlas de los reduccionismos que podrían presentarse ante poblaciones vulnerables.

El deseo de autonomía expresado por algunos pacientes encaja bien dentro del denominado 'medicalizatción del control' (White y Callahan, 2000). Es decir, con la posibilidad de tener cierto control sobre la forma de morir como último recurso para mantener el sentido de dignidad. Estudios sobre los factores que motivan la petición de suicidio asistido en Oregón (Chin et al., 1999; Ganzini et al., 2009; Lee et al., 1996) identificaron que el denominador común en estos pacientes era la importancia que atribuían a la pérdida de control sobre el momento de morir. De nuevo, la idea de autonomía como fundamento de la dignidad e identidad personal se hizo presente.

Ser auténtico, en nuestro análisis operativo, fue descrito como ser independiente y como tomar decisiones en coherencia con la historia personal. El deseo de recobrar un yo autónomo (como el que uno era antes de contraer la endermedad) puede reflejarse en lo que denominamos 'identidad dividida' (*split identity*). Esta visión, que tiene su origen en el ideal romántico de autenticidad, consideraría el hecho de que el sujeto es capaz de contruirse, elegirse, dominar(se) como aquello que validaría su propia identidad (Ferrara, 1998; Taylor, 1992, 1994). Teniendo en cuenta esta perspectiva, el criterio a seguir estaría basado en esta interioridad auto-poseída que nos permitiría ser constructores de nuestro propio carácter (Taylor, 1992).

Tal y como puede verse, sería una autenticidad que aspira a no tener ni límites, ni reglas extrínsecas que le conducionen, lo que, de hecho convertiría la autenticidad en un concepto vacío de contenido. Mientras que en un nivel teórico podría pensarse que la autenticidad es un valor relevante que tiene su eco en la toma de decisiones médicas, desde un punto de vista liberal (y medicalizado) es cuestionable hasta qué punto la autencidad es un valor respetado. Con frecuencia, los criterios económicos dirigen la toma de decisiones reduciendo el campo de la elección a la combinación del valor económico-social que se atribuye a una persona (especialmente inferior para los ancianos y para la gente enferma) y lo que dentro de ese margen de actuación puede escoger. También el discurso médico ha sido asociado con procedimientos burocráticos que han sido descritos, desde la experiencia vivida, “como un intenso sentido de pérdida” (Walter, 1994, p. 9). Asimilar la autenticidad a la toma de decisiones en lugar de la capacidad de escoger dentro de sus posibilidades puede ayudar a que los pacientes pongan la atención en lo que todavía son capaces de ser y de hacer.

Por último, retomando como contexto la medicalización, es interesante destacar que teniendo en cuenta que el DAM se da en un contexto de sufrimiento y los verbatims de los participantes suelen reflejar el malestar por el que están pasando, en nuestro análisis solo se trataron los aspectos negativos de la medicalización. A pesar de que con frecuencia la medicalización se ha visto desde una perspectiva peyorativa, sería ingenuo no reconocer los aspectos positivos de la medicalización. Por ejemplo, conectando con lo que Clark (2002) señala como novedoso en el contexto de cuidados paliativos puede decirse que la identificación de nuevas formas de promoción del cuidado de las personas que se encuentran al final de la vida, el desarrollo de nuevas perspectivas sobre la condición de los pacientes con enfermedades avanzadas, el fomento de una actitud activa en el cuidado de los pacientes que se encuentran en estados avanzados de enfermedad o el diseño de planes de cuidado de acuerdo al reconocimiento de la “interdependencia del sufrimiento físico y mental” (Clark, 2002, p. 905); sin duda alguna pueden considerarse como hitos alcanzados gracias a la medicalización. Como se ha dicho, algunos de los pacientes de los estudios incluidos mencionaron que su DAM estaba estrechamente relacionado con la presencia de dolor. En este mismo sentido, la administración de fármacos para aliviar el dolor, para tratar la depresión, el dolor psico-emocional u otros tipos de enfermedades psiquiátricas pueden ser un medio eficaz para reducir el malestar que los pacientes identifican como razones por las cuales desear adelantar su muerte. De esta forma puede verse cómo la tecnología médica y un cuidado integral pueden cooperar de forma connjunta mejorando el diagnóstico y desarrollando las mejores intervenciones a la vez que se atiende y respeta la dignidad y la autenticidad de la persona.

7. ¿Puede considerarse la interrupción voluntaria de la nutrición y alimentación como una forma de deseo de adelantar la muerte?

Tras comparar los hallazgos del estudio de Bolt et al. (2015) con los de la meta-etnografía sobre el DAM, puede verse cómo el VSED, en pacientes con enfermedades avanzadas, encajaría como una forma de DAM.

En la mencionada meta-etnografía (Monforte-Royo et al., 2012) se identificaron seis temas que explicaban la presencia del DAM en pacientes en estado avanzado de enfermedad: el DAM como respuesta al sufrimiento físico, psicológico y spiritual, pérdida del yo, miedo al morir, deseo de vivir pero no de este modo, el DAM como una forma de acabar con el sufrimiento, y como una forma de controlar el proceso de final de vida (tener un 'as bajo la manga', un por si acaso). El estudio de Bolt et al. (2015) también sostiene la existencia de sufrimiento global en los pacientes que optaron por VSED. Entre los motivos descritos por los médicos de familia por los que los pacientes escogieron VSED se mencionan: los somáticos (79%), los existenciales (77%) y factores relacionados con la dependencia (58%). Otros factores mencionados fueron la "pérdida de dignidad", "pérdida del yo", factores sociales y sufrimiento de índole psiquiátrico.

Los médicos de familia percibieron el VSED de sus pacientes como una forma de acabar con el sufrimiento y como una forma de control sobre la propia vida (Bolt et al., 2015). De igual modo, los participantes de la meta-etnografía reportaron que la muerte no era vista como un fin en sí, sino como una forma de escapar de este sufrimiento insoportable. Asimismo, en algunos pacientes coexistió un deseo de morir a la vez que un deseo de vivir. Esta paradoja también puede observarse en los pacientes fallecidos por VSED, al prolongarse el proceso de deterioro (que conduce a la muerte) que, sin embargo, es en cierta manera reversible. Esta reversibilidad correspondería a la misma posibilidad de controlar el cómo y cuándo morir ("tener un as bajo la manga, un por si acaso") a la vez que puede sugerir el "deseo de vivir pero no de esta forma" descrito en la meta-etnografía (Monforte-Royo et al., 2012).

En otros estudios (Quill, 2015) también se establecen paralelismos que conectarían el VSED con el DAM tal y como fue descrito en la primera meta-etnografía sobre el DAM publicada (Monforte-Royo et al., 2012). Por ejemplo, Quill (2015) menciona la idea del suicidio asistido como el útlimo recurso frente a un sufrimiento extremo. Asimismo, desde la perspectiva de los pacientes con enfermedades avanzadas (Chochinov et al., 2002; Lavery et al., 2001; Pearlman et al., 2005) una experiencia común en ellos fue la de la “pérdida del yo”, entendido como la percepción de desintegración de la propia esencia o identidad (“ya no soy la persona que era antes de la enfermedad”). En este marco, el DAM encajaría bien como una traducción del deseo de huir de una realidad de sufrimiento, que quizá se aproxima más a la idea de self-destruction que al deseo de afirmar la propia individualidad en situaciones de fragilidad.

No obstante, se debería seguir profundizando en el significado del VSED y realizar una revisión exhaustiva de todos los estudios realizados en pacientes sobre este tema.

Capítulo 12. Implicaciones para la práctica, líneas de investigación y propuestas de futuro

Las distintas terapias o modelos de dignidad que se han desarrollado hasta el momento reflejan bien el impacto positivo sobre quienes las reciben (Brown et al., 2011; Chochinov, 2007; Chochinov et al., 2002; Guo y Jacelon, 2014; Östlund et al., 2012). La observación de que su percepción es vulnerable a diversos factores externos debería orientar algunos aspectos concretos para su cuidado y preservación [de la dignidad]. Estas medidas preventivas o terapéuticas deberían contemplar las distintas áreas a través de las cuales los pacientes perciben su dignidad. Por ejemplo, a la luz de los resultados de la revisión sistemática sobre dignidad y autonomía (Rodríguez-Prat et al., 2016), destacó cómo la pérdida de funcionalidad física ligada al ser dependiente o verse como una carga para los demás, es uno de los factores que más influyen en la pérdida de percepción de dignidad. En este sentido, anticipar su posible frustración y proporcionar estrategias para que puedan tomar decisiones y ser autónomos, puede resultar muy beneficioso.

Los datos que se han analizado en esta revisión pueden servir, a los profesionales de la salud, de guía práctica para mirar 'al otro' teniendo en cuenta su dignidad intrínseca. Esta toma de conciencia sobre la dignidad personal podría trasladarse a los cuidadores, familiares e incluso a la sociedad entera ya que a distintos niveles, cada uno de ellos puede influir en que una persona se sienta digna o no. Esta mirada puede favorecer el bienestar y autopercepción del propio paciente, familiar e incluso profesional. En consecuencia, parece necesario desarrollar planes de atención individualizados que contemplen esta forma de atender y tratar a los pacientes, así como formar a profesionales desde esta perspectiva.

Teniendo en cuenta la influencia del entorno familiar y social inmediato y a pesar de que existen numerosos modelos de dignidad centrados en los pacientes (Chochinov et al., 2002; Enes, 2003; Franklin et al., 2006; Jacelon, 2003; Jacobson, 2009b), se ha indagado poco en las estrategias que pueden desarrollar los miembros de la familia para salvaguardar esta percepción de dignidad en sus seres queridos. Asimismo, aunque existen estudios cuantitativos que han analizado el deseo de control en pacientes al final de la vida, en nuestro conocimiento, no hay estudios que exploren la experiencia y significado atribuido a este deseo desde la voz de los propios pacientes. Profundizar sobre la naturaleza de esta voluntad de control, analizar cómo se relaciona con la percepción de pérdida de dignidad y con el DAM, puede ayudar a diseñar intervenciones para aminorar esta pérdida del sentido de la propia identidad o dignidad en relación a la autonomía y al DAM.

El DAM como fenómeno complejo con sus reasons, meanings and functions también requiere la formación adecuada de los profesionales de salud para responder y comprender el impacto que supone vivir enfermedad avanzada. Conocer los factores que conducen a la emergencia del DAM puede ayudar no solo para tratarlo sino también para prevenirlo.

Recientemente se ha suscitado (Villavicencio-Chávez et al., 2014) la idea de que preguntar proactivamente sobre el DAM podría ser beneficioso para los pacientes. Sin ambargo, son necesarios más estudios para poder probarlo. Teniendo en cuenta que los factores sociales contribuyen a la emergencia del DAM, son necesarios más estudios que exploren cómo los familiares o cuidadores viven el DAM expresado por los pacientes y qué significado tiene para ellos. Asimismo, es necesario que se diseñen guías o protocolos que de forma sistemática puedan abordar el DAM que ayuden a los profesionales de la salud a atender a estos pacientes.

De forma concreta, desde un punto de vista empírico (contexto clínico) algunas de las propuestas de investigación futuras son:

- Analizar la relación entre percepción de dignidad, control y deseo de adelantar la muerte en pacientes con cáncer avanzado.

- Comprender el deseo de control en estos pacientes. Explorar de qué forma el deseo de control o de autonomía se relaciona con el deseo de adelantar la muerte que puedan presentar. Y, explorar las necesidades de los pacientes que expresan mayor deseo de control.

Para ello se ha diseñado un estudio mixto con una primera fase cuantitativa en las que se están administrando cuestionarios para evaluar estas variables (dignidad, control y DAM) y una segunda fase cualitativa, en la que a través de entrevistas en profundidad (con un disñeo fenomenológico) se pretende profundizar en el significado atribuido a este deseo de control que muestran algunos de los pacientes. En la actualidad, este estudio está en marcha y cuenta con la financiación de Recercaixa 2015 (ver Anexo 2).

- Explorar, a través de métodos cualitativos, la vivencia de los cuidadores ante el DAM que puedan presentar los pacientes.

Desde un punto de vista filosófico:

- Examinar el uso terapéutico de la palabra en el contexto del abordaje del deseo de adelantar la muerte, prestando atención a algunos de los mecanismos sugeridos en la literatura biomédica a la luz del legado filosófico y literario clásico y contemporáneo sobre el poder curativo de la palabra. Por un lado, prestando especial atención a la obra del médico y humanista Laín Entralgo (1908-2001). Y, por otro, a la pragmática del lenguaje, es decir, al uso del lenguaje como elemento transformativo de la realidad, de las convicciones o estado de ánimo de las personas.

Capítulo 13. Conclusiones

- A pesar de que la dignidad puede considerarse intrínseca al ser humano, su percepción, partiendo de esta revisión sistemática, se presenta como un concepto complejo, multidimensional y dinámico, especialmente relacionado con la noción de identidad personal. Entender en profundidad el contexto vivencial de estos pacientes puede ayudar a no reducirlos a sus circunstancias y, dada la vulnerabilidad que el sentido de dignidad personal muestra a algunos factores externos, deberían desarrollarse planes de cuidado que contemplaran las áreas a través de las cuales los pacientes perciben su dignidad, para mejorar así su calidad de vida y bienestar.

- La dignidad, mediada por la autonomía, control o autodeterminación, en este contexto de enfermedad avanzada es un fenómeno dinámico y encarnado dentro de las coordenadas yo-cuerpo-otros-mundo. Analizar esta experiencia a través de las verbatims de los estudios cualitativos permite mostrar cómo a través de los reportes generados por los pacientes se puede comprehender la experiencia de la enfermedad. Profundizar sobre el contexto experiencial de las personas que se encuentran al final de su vida puede contribuir a que los pacientes no sean mirados exclusivamente como cuerpos objetivos ni reducidos a sus circunstancias de enfermedad. Teniendo en cuenta que la percepción de dignidad se ve condicionada por muchos factores, desarrollar planes de cuidado que consideren ‘la mirada fenomenológica’ contribuirá a salvaguardar la dignidad de los pacientes (y de sus familias) que redundará en una mejora de la calidad de vida.

- El DAM en pacientes con enfermedad avanzada no puede entenderse fuera de la experiencia de sufrimiento, siendo éste un requisito necesario para su aparición en esta población. Detrás de cada expresión de DAM existe un porqué y un para qué que justifica este deseo en los pacientes que lo presentan. Asimismo, el DAM puede tener un significado diferente para cada paciente en función de su propia experiencia vivida y entorno cultural, que no implica necesariamente un deseo de la muerte en sí. La expresión del DAM en países donde la eutanasia o suicidio asistido están despenalizados, fue también un medio para acabar con el sufrimiento. Todo ello nos sugiere la necesidad de explorar individualmente las razones, los significados y las funciones atribuidos a este deseo de morir para comprender la naturaleza del DAM en cada paciente y poder diseñar planes de atención individualizada.

- En este contexto de sufrimiento en personas que se encuentran al final de la vida, el VSED puede comprenderse como una manifestación del DAM. Por lo tanto, explorar la sintomatología depresiva y otros factores psico-emocionales, así como los aspectos sociales y existenciales-espirituales es imprescindible para no interpretar este acto simplemente como una expresión de autonomía personal sino como un indicador de sufrimiento.

- El impacto de la medicalización está presente en la experiencia de los pacientes que expresan DAM y modula las representaciones sobre el sufrimiento, el proceso de final de vida y la muerte. En este ámbito, es necesario que los profesionales de la salud conozcan la experiencia vivida, los presupuestos y los valores de los pacientes para dar una respuesta adecuada a sus necesidades y devolverles esta “dignidad social” que a menudo manifiestan haber perdido. Fomentar una idea de la autenticidad basada en la toma de decisiones por la cual la persona todavía sigue teniendo margen para la acción, puede contribuir a mirar este proceso de final de vida como un momento en el que también se le puede encontrar un sentido a la vida.

Conclusions

- Despite the fact that dignity can be seen as intrinsic to mankind, our perception of it, based on this systematic revision, is presented as a complex, multidimensional and dynamic concept. What's more it is closely linked to the notion of personal identity. Fully understanding the context of these patients' lives may help us to not reduce them to their circumstances. Also, given the vulnerability of a person's sense of personal dignity to some external factors, care plans that take into account the areas through which patients perceive their dignity, in order to improve their quality of life and wellbeing should be developed.

- Dignity, mediated by autonomy and control or self-determination, in the context of advanced illness is a dynamic phenomenon manifested within the coordinates self-body-others-world. Analysing this experience through the verbatims from the qualitative studies allows us to show how, through the reports generated by the patients, we can understand the experience of illness. Looking at the experience of people at the end of life in more depth can help these patients not to be seen exclusively as objective bodies or reduced to the circumstances of their illness. Bearing in mind that the perception of dignity is influenced by many factors, developing care plans that take the "phenomenological perspective" into account will contribute to safeguarding the dignity of patients (and their families) and will result in an improvement in quality of life.

-The wish to hasten death (WTHD) in patients with advanced illness cannot be understood outside of the experience of suffering, given that this is a necessary requirement for its emergence in this population. Behind each expression of the WTHD there are reasons and functions that justify this desire in the patients that present it. Furthermore, the WTHD can have a different meaning for each patient according to their experience and cultural context; this does not necessarily entail a desire to die. The expression of the WTHD in countries where euthanasia and assisted suicide are decriminalised, was also a way of ending suffering. All of the above suggests that there is a need to explore the reasons, meaning and functions attributed to this wish in order to understand the nature or the WTHD in each patient and to be able to design individualised care plans.

- The impact of the medicalisation is present in the experience of the patients who express the WTHD and it regulates the representations of suffering, the process of the end of life and death. In this field of suffering, it is necessary for health care professionals to know and understand patients' experiences, assumptions and values in order to respond appropriately to their needs and give them back the "social dignity" which they have often lost. Fostering an idea of authenticity based on decision making, through which the person still has a margin for action, can contribute to seeing the process of the end of life as a moment in which we can find meaning.

- In this context of suffering in people at the end of life, VSED can be understood as a manifestation of the WTHD. As such, exploring symptoms of depression and other psycho-emotional factors as well as social an existential-spiritual aspects is indispensable in order to not interpret this act simply as an expression of personal autonomy but rather as an indicator of suffering.

Capítulo 14. Producción científica

14.1 Artículos originales que constituyen esta tesis doctoral

Prólogo. Rodríguez-Prat A, Monforte-Royo C. 25 years after Intoxicated by My Illness. Challenges for Medical Humanities. *Lancet*. 2017;*389*(10066):249-250.

Datos bibliométricos: Factor de impacto: 44.002 (2015). ISI Journal Citation Reports®: Medicine, General & Internal, posición 2 de 155 (1er cuartil).

Primer artículo. Rodríguez-Prat A, Monforte-Royo C, Porta-Sales J, Escribano X, Balaguer A. Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography. *PLoS One*. 2016;*11*(3):e0151435. doi: 10.1371/journal.pone.0151435.

Datos bibliométricos: Factor de impacto: 3.057 (2015). ISI Journal Citation Reports®: Multidisciplinary Sciences, posición 11 de 63 (1er cuartil).

Segundo artículo. Rodríguez-Prat A, Escribano X. A philosophical view on the experience of dignity and autonomy through the phenomneology of illness. J *Med Philos*. 2017. (Aceptado, 14 febrero).

Datos bibliométricos: Factor de impacto: 1.293 (2015). ISI Journal Citation Reports®: Ethics, posición 16 de 51 (2ndo cuartil).

Tercer artículo. Rodríguez-Prat A, Balaguer A, Booth A, Monforte-Royo C. Understanding patients' experiences of the wish to hasten death: An updated and expanded systematic review and meta-ethnography. *BMJ Open*. 2017 [Pendiente de recibir la decisión final por parte del editor desde el 16 de mayo 2017].

Datos bibliométricos: Factor de impacto: 2.562 (2015). ISI Journal Citation Reports®: Medicine, General & Internal, posición 32 de 155 (1r cuartil).

Cuarto artículo. Rodríguez-Prat A, van Leeuwen E. Assumptions and moral understanding of the wish to hasten death: a philosophical review of qualitative studies. *Med Heal Care Philos*. 2017. [Reenvío del manuscrito tras haber recibido correciones: 28 de Marzo de 2017]

Datos bibliométricos: Factor de impacto: 0.974 (2015). ISI Journal Citation Reports®: History & Philosophy of Science, posición 9 de 44 (1r cuartil).

Quinto artículo. Rodríguez-Prat A, Monforte-Royo C, Balaguer A. Ethical challenges for an understanding of suffering: Voluntary stopping of eating and drinking and the wish to hasten death in advanced patients

14.2 Publicaciones derivadas de congresos

Rodríguez-Prat A, Balaguer A, Monforte-Royo C. Comprehending patients' experiences of the WTHD: A systematic review and meta-ethnography. 15th World Congress of the European Association for Palliative Care. 18-20 May. Madrid, Spain. *European Journal of Palliative Care.* p. 350.

Rodríguez-Prat A, Crespo I, Tomás-Sábado J, Monforte-Royo C, Porta-Sales J, Balaguer A. Dignity, control and with to hasten death in patients with advanced cancer. 15th World Congress of the European Association for Palliative Care. 18-20 May. Madrid, Spain. *European Journal of Palliative Care.* p. 135.

Porta-Sales J, Crespo I, Monforte-Royo C, Guerrero-Torrelles M, **Rodríguez-Prat A**, Balaguer A. Frequency and intensity assessment of the wish to hasten death in patients with advanced cancer. 15th World Congress of the European Association for Palliative Care. 18-20 May. Madrid, Spain. *European Journal of Palliative Care*. p. 356.

Crespo I, Monforte-Royo C, **Rodríguez-Prat A**, Guerrero-Torrelles M, Balaguer A, Porta-Sales J. Proactive assessment of the wish to hasten death: What do patients think? 15th World Congress of the European Association for Palliative Care. 18-20 May. Madrid, Spain. *European Journal of Palliative Care.* p. 358.

Rodríguez-Prat A, Monforte-Royo C, Balaguer A. Assumptions on dignity and the value of life in terminally ill patients. A review of argument-based ethics literature. Palliat Med. 2016: NP199-200. 9th World Research Congress of the European Association for Palliative Care. Dublin; 9-11 June 2016. DOI: 10.1177/0269216316646056.

Guerrero M, **Rodríguez-Prat A**, Porta-Sales J, Balaguer A, Monforte-Royo C. Recomendaciones para abordar el deseo de adelantar la muerte: una revisión sistemática de la literatura. En: Actas de congreso: XI Congreso Internacional de la Sociedad Española de Cuidados Paliativos (SECPAL); 12-14 Mayo 2016. Sevilla. pp. 429. ISBN: 978-84-608-6003-7.

Rodríguez-Prat A, Monforte-Royo C, Escribano X, Porta J, Balaguer A. Relationship between perceived dignity and autonomy at the end of life: results of a meta-ethnographic study. In: Book of abstracts EAPC 2015. 14th World Congress of the European Association for Palliative Care. 8-10 May. Copenhagen, Denmark. Newmarket, UK: Hayward Group Ltd. p.53. ISBN: 978-0-9542022-3-1.

Rodríguez-Prat A, Monforte-Royo C, Porta Sales J, Balaguer A. Relación entre dignidad percibida y autonomía al final de la vida: resultados preliminares de una metaetnografía. En: Libro de resúmenes de comunicaciones. X Congreso Nacional de la Sociedad Española de Cuidados Paliativos. Madrid 13-15 Noviembre 2014; pp.53.

14.3 Comunicaciones presentadas en congresos

Rodríguez-Prat A, Balaguer A, Monforte-Royo C. Comprehending patients' experiences of the WTHD: A systematic review and meta-ethnography. 15th World Congress of the European Association for Palliative Care. 18-20 May. Madrid, Spain. Poster Communication.

Rodríguez-Prat A, Crespo I, Tomás-Sábado J, Monforte-Royo C, Porta-Sales J, Balaguer A. Dignity, control and with to hasten death in patients with advanced cancer. 15th World Congress of the European Association for Palliative Care. 18-20 May. Madrid, Spain. Oral communication.

Porta-Sales J, Crespo I, Monforte-Royo C, Guerrero-Torrelles M, **Rodríguez-Prat A**, Balaguer A. Frequency and intensity assessment of the wish to hasten death in patients with advanced cancer. 15th World Congress of the European Association for Palliative Care. 18-20 May. Madrid, Spain. Poster communication.

Crespo I, Monforte-Royo C, **Rodríguez-Prat A**, Guerrero-Torrelles M, Balaguer A, Porta-Sales J. Proactive assessment of the wish to hasten death: What do patients think? 15th World Congress of the European Association for Palliative Care. 18-20 May. Madrid, Spain. Poster communication.

Rodríguez Prat, A, Monforte-Royo C, Balaguer A. "Assumptions on Dignity and the Value of Life in Terminally Ill Patients. A Review of Argument-based Ethics Literature (póster). 9th World Research Congress of the European Association for Palliative Care. 9-11 June 2016. Dublin, Ireland.

Guerrero-Torrelles, M, **Rodríguez-Prat, A**, Porta Sales J, Balaguer A, Monforte-Royo C (póster). Recomendaciones para abordar el deseo de adelantar la muerte: una revisión sistemática de la literatura. XI Congreso Nacional de la Asociación Española de Cuidados Paliativos, 12-14 Mayo de 2016. Sevilla, Spain.

Teresa Vallès-Botey and **Andrea Rodríguez-Prat**, 'The Character of Job and the Desire to Understand the Suffering' (Comunicación oral), Universitat Internacional de Catalunya, en la International conference of the Association for Core Texts and Courses. Atlanta, Georgia, USA on April 14-17th, 2016.

Rodríguez-Prat, Andrea, De l'experiència de la dignitat al final de la vida a la fenomenologia de la corporalitat de K. Toombs (comunicación oral). IV Congrès Català de filosofia. Vilafranca del Penedès, 25-27 de noviembre de 2015.

Rodríguez-Prat, A. La anticipación del dolor en pacientes al final de la vida. Jornades Fenomenología del dolor. UIC Barcelona. 17 de noviembre de 2015.

Teresa Vallès Botey, Blanca Ballester, **Andrea Rodríguez-Prat,** 'Core texts and big questions for Health Undergraduates. The case of the biblical Job' (Comunicación oral), en el congreso Liberal Arts and Sciences Education and Core Texts in the European Context, 11-12 de septiembre de 2015, Amsterdam University College.

Rodríguez Prat, A, Monforte-Royo C, Porta Sales J, Balaguer A. Relación entre dignidad percibida y autonomía al final de la vida: resultados preliminares de una meta-etnografía. X Congreso Nacional de Cuidados Paliativos. 13-15 Noviembre 2014. Comunicación oral.

Rodríguez Prat, A, Monforte-Royo C, Escribano X, Porta Sales J, Balaguer A. Relationship between perceived dignity and autonomy at the end of life: results of a meta-ethnographic study. 9th World Congress European Association Palliative Care, 13-15 de mayo 2015, Copenhagen: Comunicación oral.

14.4 Artículos complementarios

Guerrero-Torrelles M, Monforte-Royo C, **Rodríguez-Prat A**, Porta-Sales J, Balaguer A. Understanding meaning-in-life interventions: a systematic realist review. *Palliative Medicine*. 2017; doi: 10.1177/0269216316685235.

Guerrero-Torrelles M, **Rodríguez-Prat A**, Monforte-Royo C, Porta-Sales J. Responder al deseo de adelantar la muerte en pacientes al final de la vida: Síntesis de recomendaciones y guías clínicas. *Medicina Paliativa*. (Aceptado, 16 septiembre).

Rodríguez-Prat A. (2017) Anticipación del dolor en pacientes al final de la vida. *Health Aging and End of Life, 2* (in print).

14.5 Capítulos de libro

Vallès-Botey T, **Rodríguez-Prat A**. Core Texts and Big Questions for Health Undergraduates. The Cases of Job and King Lear. En: Cohen de Lara E, Drop H, eds. “Back to the Core: Rethinking Core Texts in Liberal Arts & Sciences Education in Europe.” Delaware: Vernon Press; 2017.

Rodríguez-Prat A, Escribano X. A humanistic perspective on the curative power of language at the end of life: Restoration of the self through words and silence. En: L. Scholl, ed. *Medicine and What It Means to Be Human*. Routledge; 2018 (en proceso).

Referencias

Abiven, M. (1990). Dying with dignity. *World Health Forum*, *12*(4), 375–381.

Akechi, T., Okamura, H., Yamawaki, S., y Uchitomi, Y. (2001). Why do some cancer patients with depression desire an early death and others do not? *Psychosomatics*, *42*(2), 141–145.

Albers, G., Pasman, H. R. W., Rurup, M. L., y Vet, H. C. W. De. (2011). Analysis of the construct of dignity and content validity of the patient dignity inventory. *Health and Quality of Life Outcomes*, *9*(1), 45. doi:10.1186/1477-7525-9-45

Albert, S. M., Rabkin, J. G., Del Bene, M. L., Tider, T., O'Sullivan, I., Rowland, L. P., y Mitsumoto, H. (2005). Wish to die in end-stage ALS. *Neurology*, *65*(1), 68–74.

Améry, J. (1976). *Levantar la mano sobre uno mismo. Discurso sobre la muerte voluntaria* (2ª ed.). Stuttgart: Pre-Textos.

Andrés, R. (2016). *Semper dolens. Historia del suicidio en Ocidente*. Barcelona: Acantilado.

Ariès, P. (1984). *El hombre ante la muerte*. Barcelona: Taurus.

Ariès, P. (2005). *Historia de la muerte en Occidente: desde la Edad Media hasta nuestros días* (3ª ed.). Barcelona: Acantilado.

Aristóteles. (1987). *Acerca de la generación y la corrupción; Tratados breves de historia natural*. Madrid: Gredos.

Aristóteles. (2003). *Acerca del alma*. Madrid: Gredos.

Arregui, J. V. (1994). *El horror a morir*. Barcelona: Ed. Tibidabo.

Ashcroft, R. E. (2005). Making sense of dignity. *Journal of Medical Ethics*, *31*(11), 679–682. doi: 10.1136/jme.2004.011130

Asociación Americana de Psiquiatría. (2014). Actualización de la codificación del DSM-5®. Acceso 8 mayo 2017. Disponible en: http://psychiatryonline.org/pb/assets/raw/dsm/pdf/Spanish_DSM-5 Coding Update_Final.pdf

Aujoulat, I., Marcolongo, R., Bonadiman, L., y Deccache, A. (2008). Reconsidering patient empowerment in chronic illness: A critique of models of self-efficacy and bodily control. *Social Science & Medicine*, *66*(5), 1228–1239. doi:10.1016/j.socscimed.2007.11.034

Bakitas, M. A. (2005). Self-Determination: Analysis of the Concept and Implications for Research in Palliative Care. *Canadian Journal of Nursing Research*, *37*(2), 22–49.

Balaguer, A., Monforte-Royo, C., Porta-Sales, J., Alonso-Babarro, A., Altisent, R., Aradilla-Herrero, A., Bellido-Pérez, M., Breitbart, W., Centeno, C, Cuervo M. A., Deliens, L., Frerich, G., Gastmans, C., Lichtenfeld, S., Limonero, J. T., , Materstvedt, L. J., Nabal, M., Rodin, G., Rosenfeld, B., Schroepfer, T., Tomás-Sábado, J., Trelis, J., Villavicencio-Chávez, C., Voltz, R. (2016). An international consensus definition of the wish to hasten death and its related factors. *PLoS ONE*, *11*(1), 1–14. doi:10.1371/journal.pone.0146184

Batavia, A. I. (2000). So far so good: Observations on the first year of Oregon’s Death with Dignity Act. *Psychology, Public Policy, and Law*, *6*(2), 291–304. doi:10.1037//1076-8971.6.2.291

Battin, M. P. (1995). *Ethical Issues in Suicide*. Englewood Cliffs: Pearson Education.

Baudrillard, J. (1980). *El intercambio simbólico y la muerte*. Caracas: Monte Ávila Editores.

Bayer, T., Tadd, W., y Krajcik, S. (2005). Dignity: The voice of older people. *Quality in Ageing - Police, Practice and Research*, *6*(1), 22–29.

Bayertz, K. (1996). *Sanctity of life and Human Dignity*. Dordrecht: Kluwer Academic Pulishers.

Bayés, R. (2003). La sociedad contemporánea ante el sufrimiento y la muerte. *Humanitas, Humanidades Médicas*, *1*(1), 53–74.

Beauchamp, T. L., y Childress, J. (1979). *Principles of biomedical ethics.* Oxford: Oxford University Press.

Bellido-Pérez, M., Monforte-Royo, C., Tomás-Sábado, J., Porta-Sales, J., y Balaguer, A. (2017). Assessment of the wish to hasten death in patients with advanced disease: a systematic review of measurement instruments. *Palliative Medicine*. *31*(6), 510–525. doi: 10.1177/0269216316669867

Blackhall, L. J. (1995). Ethnicity and Attitudes towards Patient Autonomy. *Journal of American Medical Association*, *274*(10), 820–825.

Bolt, E. E., Hagens, M., Willems, D., y Onwuteaka-Philipsen, B. D. (2015). Primary care patients hastening death by voluntarily stopping eating and drinking. *Annals of Family Medicine*, *13*(5), 421–428. doi:10.1370/afm.1814

Breitbart, W., Rosenfeld, B., Pessin, H., Kaim, M., Funesti-Esch, J., Galietta, M., Nelson, C. J., y Brescia, R. (2000). Depression, Hopelessness, and Desire for Hastened Death in Terminally Ill Patients With Cancer. *Journal of American Medical Association*, *284*(22), 2907–2911.

Brotea, J. (2011). *Alluring freedoms: Heideggerian for an ethical encounter with dying and death* (Doctoral thesis). Carleton University.

Brown, H., Johnston, B., y Östlund, U. (2011). Identifying care actions to conserve dignity in end-of-life care. *British Journal of Community Nursing*, *16*(5), 238–245.

Broyard, A. (1990). *Ebrio de enfermedad y otros escritos de vida y muerte* (2ª ed.). Segovia: La uña rota.

Callahan, D. (1989). Can we return death to disease? *The Hastings Center Report*, *19*(1), 4–6.

Callahan, D. (1992). When self-Determination Runs Amok. *The Hastings Center Report*, *22*(2), 52–55.

Callahan, D. (2002). A commentary-Putting autonomy in its place: developing effective guidelines. *The Gerontologist*, *42*(3), 129–131.

Camus, A. (1985). *El mito de Sísifo*. Madrid: Alianza.

Carel, H. (2006). *Life and death in Freud and Heidegger*. New York; Amsterdam: Rodopi.

Carel, H. (2007). Can I be ill and happy? *Philosophia*, *35*(2), 95–110.

Carel, H. (2011). Phenomenology and its application in medicine. *Theoretical Medicine and Bioethics*, *32*(1), 33–46. doi:10.1007/s11017-010-9161-x

Carel, H., y Cooper, R. (2013). *Health, Illness and Disease.* Durham: Acumen.

Casell, E. (1982). The nature of suffering and the goals of medicine. *New England Journal of Medicine*, *306*(11), 639–645.

Chabot, B. E., y Goedhart, A. (2009). A survey of self-directed dying attended by proxies in the Dutch population. *Social Science and Medicine*, *68*(10), 1745–1751. doi: 10.1016/j.socscimed.2009.03.005

Chapple, A., y Ziebland, S. (2006). What people close to death say about euthanasia and assisted suicide: a qualitative study. *Journal of Medical Ethics*, *32*(12), 706–710. doi: 10.1136/jme.2006.015883

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, *5*(2), 168–197.

Charmaz, K. (1995). The Body, Identity, and Self: Adapting To Impairment. *Sociological Quarterly*, *36*(4), 657–680.

Chin, A. E., Hedberg, K., Higginson, G. K., y Fleming, D. W. (1999). Legalized Physician-Assisted Suicide in Oregon — The First Year’s Experience. *The New England Journal of Medicine*, *340*(7), 577–583.

Chochinov, H. M. (2002). Dignity-conserving care — a new model for palliative care: helping the patient feel valued. *JAMA*, *287*(17), 2253–2260.

Chochinov, H. M. (2004). Dignity and the eye of the beholder. *Journal of Clinical Oncology*, *22*(7), 1336–1340. doi: 10.1200/JCO.2004.12.095

Chochinov, H. M. (2007). Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. *BMJ*, *335*(7612), 184–7. doi: 10.1136/bmj.39244.650926.47

Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., y Harlos, M. (2002). Dignity in the terminally ill: a cross-sectional, cohort study. *Lancet*, *360*(9350), 2026–2030. doi: 10.1016/S0140-6736(02)12022-8

Chochinov, H. M., Hack, T., McClement, S., Kristjanson, L., y Harlos, M. (2002). Dignity in the terminally ill: A developing empirical model. *Social Science and Medicine*, *54*(3), 433–443.

Chochinov, H. M., Hassard, T., Mcclement, S., Hack, T., Kristjanson, L. J., Harlos, M., Sinclair, S., Murray, A. (2008). The Patient Dignity Inventory: A Novel Way of Measuring Dignity-Related Distress in Palliative Care. *Journal of Pain and Symptom Management*, *36*(6), 559–571. doi: 10.1016/j.jpainsymman.2007.12.018

Chochinov, H. M., Kristjanson, L. J., Hack, T. F., Hassard, T., McClement, S., y Harlos, M. (2007). Burden to others and the terminally ill. *Journal of Pain and Symptom Management*, *34*(5), 463–471. doi: 10.1016/j.jpainsymman.2006.12.012

Chochinov, H. M., Tataryn, D., Clinch, J. J., y Dudgeon, D. (1999). Will to live in the terminally ill. *Lancet*, *354*(9181), 816–819. doi: 10.1016/S0140-6736(99)80011-7

Chochinov, H. M., Wilson, K. G., Enns, M., Mowchun, N., Lander, S., Levitt, M., y Clinch, J.J. (1995). Desire for death in the terminally ill. *American Journal of Psychiatry*, *152*, 1185–1191.

Choza, J. (1991). *Conciencia y afectividad: Aristóteles, Nietzsche, Freud* (2^{a} ed.). Pamplona: EUNSA.

Clark, D. (2002). Between hope and acceptance: the medicalisation of dying. *BMJ*, *13*(324), 905–907. doi: 10.1136/bmj.324.7342.905

Coenen, A., Doorenbos, A. Z., y Wilson, S. A. (2007). Nursing interventions to promote dignified dying in four countries. *Oncology Nursing Forum*, *34*(6), 1151–1156. doi: 10.1188/07.ONF.1151-1156

Colomer, E. (1986), *El Pensamiento alemán de Kant a Heidegger*. Volumen 3. Barcelona: Herder.

Compassion & Choices. (2008). Why Physicians & The American Public Health Association Support Death with Dignity. Acceso 7 enero 2015. Disponible en: https://www.compassionandchoices.org/userfiles/Why-Physicians-Support-Aid-In-Dying.pdf

Conrad, P. (2008). *The medicalization of society: On the transformation of human conditions into treatable disorders*. Baltimore: JHU Press.

Cooper, C. M. (1997). Death with dignity. *Hasting Center Report*, *27*(5), 37–38.

Coward, H. G., y Stajduhar, K. I. (2012). *Religious understandings of a good death in hospice palliative care*. New York: State University of New York Press.

Coyle, N., y Sculco, L. (2004). Expressed desire for hastened death in seven patients living with advanced cancer: a phenomenologic inquiry. *Oncology Nursing Forum*, *31*(4), 699–709.

Crigger, B.-J., Wolf, S. M., Bopp, J. J., Scofield, G., y Ellman, I. M. (1990). The Court & Nancy Cruzan. *Hasting Center Report*, *20*(1), 38–50.

Davis, D. F. (2008). Human Dignity and Respect for Persons: A Historical Perspective on Public Bioethics. In President's Council on Bioethics. En *Human dignity and Bioethics. Essays Commissioned by the President's Council on Bioethics*. Washington, D.C.

Death with dignity. (1982). *The American Public Health Association*, *72*(2), 204. Acceso 24 Mayo 2017. Disponible en:

http://ajph.aphapublications.org/doi/pdf/10.2105/AJPH.72.2.183

Dees, M. K., Vernooij-Dassen, M. J., Dekkers, W. J., Vissers, K. C., y van Weel, C. (2011). “Unbearable suffering”: a qualitative study on the perspectives of patients who request assistance in dying. *Journal of Medical Ethics*, *37*(12), 727–734. doi: 10.1136/jme.2011.045492

Delmar, C. (2013). The interplay between autonomy and dignity: summarizing patients voices. *Medicine, Health Care, and Philosophy*, *16*(4), 975–981. doi: 10.1007/s11019-012-9416-6

Delmar, C., Bøje, T., Dylmer, D., Forup, L., Jakobsen, C., Møller, M., Sønder, H., y Pedersen, B. D. (2005). Achieving harmony with oneself: life with a chronic illness. *Scandinavian Journal of Caring Sciences*, *19*(3), 204–212.

Doorenbos, A. Z., Wilson, S. A, y Coenen, A. (2006). A cross-cultural analysis of dignified dying. *Journal of Nursing Scholarship*, *38*(4), 352–357.

Drought, T. S., y Koenig, B. A. (2002). “Choice” in end-of-life decision making: researching fact or fiction? *The Gerontologist*, *42*(3), 114–128.

Emanuel, E. J., y Emanuel, L. L. (1998). The promise of a good death. *Lancet*, *351*, 21–29.

Emanuel, E. J., Fairclough, D. L., y Emanuel, L. L. (2000). Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA*, *284*(19), 2460–2468.

Enes, S. P. D. (2003). An exploration of dignity in palliative care. *Palliative Medicine*, *17*(3), 263–269.

Ferrara, A. (1998). *Reflective authenticity. Rethinking the project of modernity* (1ª ed.). London; New York: Routledge.

Feyto, L. (2011). Fundamentos de bioética, de Diego Gracia. *Bioètica & Debat*, *17*(64), 8–11.

Foucault, M. (1978). *El nacimiento de la clínica: una arqueología de la mirada* *médica*. Madrid: Siglo XXI.

France, E. F., Ring, N., Noyes, J., Maxwell, M., Jepson, R., Duncan, E., Turley, R., Jones, D., y Uny, I. (2015). Protocol-developing meta-ethnography reporting guidelines (eMERGe). *BMC Medical Research Methodology*, *15*, 103. doi: 10.1186/s12874-015-0068-0

France, E. F., Wells, M., Lang, H., y Williams, B. (2016). Why, when and how to update a meta-ethnography qualitative synthesis. *Systematic Reviews*, *5*(1), doi: 10.1186/s13643-016-0218-4

Franklin, L., Ternestedt, B., y Nordenfelt, L. (2006). Views on dingity of elderly nursing home residents. *The Hastings Center Report*, *13*(2). doi: 10.1191/0969733006ne851oa

Galushko, M., Strupp, J., Walisko-Waniek, J., Hahn, M., Löffert, S., Ernstmann, N., Pfaff, H., Radbruch, L., Nauck, F., Ostgathe, C., y Voltz, R. (2015). Validation of the German version of the Schedule of Attitudes Toward Hastened Death (SAHD-D) with patients in palliative care. *Palliative and Supportive Care*, 713–723. doi: 10.1017/S1478951514000492

Ganzini, L., Beer, T. M., y Brouns, M. C. (2006). Views on physician-assisted suicide among family members of Oregon cancer patients. *Journal of Pain and Symptom Management*, *32*(3), 230–236. doi: 10.1016/j.jpainsymman.2006.04.004

Ganzini, L., Dobscha, S. K., Heintz, R. T., y Press, N. (2003). Oregon Physicians' Perceptions of Patients Who Request Assisted Suicide and Their Families. *Journal of Palliative Medicine*, *6*(3), 381–390.

Ganzini, L., Goy, E. R., y Dobscha, S. K. (2009). Oregonians' reasons for requesting physician aid in dying. *Archives of Internal Medicine*, *169*(5), 489–492. doi: 10.1001/archinternmed.2008.579

Ganzini, L., Goy, E. R., Miller, L. L., Harvath, T. A, Jackson, A., y Delorit, M. A. (2003). Nurses' experiences with hospice patients who refuse food and fluids to hasten death. *The New England Journal of Medicine*, *349*(4), 359–

365. doi: 10.1056/NEJMsa035086

Ganzini, L., Harvath, T. A., Jackson, A., Goy, E. R., Miller, L. L., y Delorit, M. A. (2002). Experiences Of Oregon Nurses And Social Workers With Hospice Patients Who Requested Assistance With Suicide. *New England Journal of Medicine*, *347*(8), 582–588.

Ganzini, L., Silveira, M. J., y Johnston, W. S. (2002). Predictors and correlates of interest in assisted suicide in the final month of life among ALS patients in Oregon and Washington. *Journal of Pain and Symptom Management*, *24*(3), 312–317.

Goodin, R. (1981). The Political Theories of Choice and Dignity. *American Philosophical Quarterly*, 91–95.

Gordts, E. (14 Enero 2013). Marc And Eddy Verbessem, Deaf Belgian Twins, Euthanized After Starting To Turn Blind. *The Huffington Post*. Disponible en: http://www.huffingtonpost.com/2013/01/14/marc-eddy-verbessem-belgium-euthanasia_n_2472320.html

Gorer, G. (1955). The pornography of death. *Encounter*, 49–52.

Guerrero-Torrelles, M., Monforte-Royo, C., Rodríguez-Prat, A., Porta-Sales, J., y Balaguer, A. (2017). Understanding meaning in life interventions in advanced illness patients: A systematic review and realist synthesis. doi: 10.1177/0269216316685235

Guerrero-Torrelles, M., Monforte-Royo, C., Tomás-Sábado, J., Marimon, F., Porta-Sales, J., y Balaguer, A. (2017). Meaning in life as a mediator between physical impairment and the wish to hasten death in patients with advanced cancer. *Journal of Pain and Symptom Management* [Aceptado].

Guo, Q., y Jacelon, C. S. (2014). An integrative review of dignity in end-of-life care. *Palliative Medicine*, *28*(7), 931–940. doi: 10.1177/0269216314528399

Hack, T. F., Chochinov, H. M., Hassard, T., Kristjanson, L. J., McClement, S., y Harlos, M. (2004). Defining dignity in terminally ill cancer patients: a factor-analytic approach. *Psycho-Oncology*, *13*(10), 700–708. doi: 10.1002/pon.786

Haddock, J. (1996). Towards further clarification of the concept “dignity.” *Journal of Advanced Nursing*, *24*(5), 924–931.

Hall, S., Davies, J. M., Gao, W., y Higginson, I. J. (2014). Patterns of dignity-related distress at the end of life: A cross-sectional study of patients with advanced cancer and care home residents. *Palliative Medicine*. doi: 10.1177/0269216314533740

Hall, S., Edmonds, P., Harding, R., Chochinov, H., y Higginson, I. J. (2009). Assessing the feasibility, acceptability and potential effectiveness of Dignity Therapy for people with advanced cancer referred to a hospital-based palliative care team: Study protocol. *BMC Palliative Care*, *8*, 5. doi: 10.1186/1472-684X-8-5

Haugeland, J. (2000). Truth and Finitude: Heidegger’s Transcendental Existentialism. En M. Wrathall y J. Malpas (Eds.), *Heidegger, Authenticity, and Modernity. Essays in Honor if Hubert L. Dreyfus. Volume 1*. Cambridge: Massachusetts Institute of Technology Press.

Heidegger, M. (1951). *Ser y tiempo* [trad. José Gaos]. Madrid: Fondo de Cultura Económica.

Hendin, H. (2009). *Seducidos por la muerte. Médicos, pacientes y suicidio asistido*. Barcelona: Planeta.

Hendin, H., Foley, K., y White, M. (1998). Physician-assisted suicide: reflections on Oregon’s first case. *Issues in Law and Medicine*, *14*, 243.

History of death with dignity. (s.f). Acceso 9 Enero 2017. Disponible en: http://www.deathwithdignity.org/history

Ho, A. H. Y., Chan, C. L. W., Leung, P. P. Y., Chochinov, H. M., Neimeyer, R. A., Pang, S. M. C., y Tse, D. M. W. (2013). Living and dying with dignity in Chinese society: Perspectives of older palliative care patients in Hong

Kong. *Death Studies*, *42*(4), 455–461. doi: 10.1093/ageing/aft003

Ho, A. H. Y., Leung, P. P. Y., Tse, D. M. W., Pang, S. M. C., Chochinov, H. M., Neimeyer, R. A., y Chan, C. L. W. (2013). Dignity Amidst Liminality: Healing Within Suffering Among Chinese Terminal Cancer Patients. *Death Studies*, *37*(10), 953–970. doi: 10.1080/07481187.2012.703078

Hobbes, T. (1914). Of Power, Worth, Dignity, Honour, and Worthiness. En *Leviathan*. New York: The Harvard Classics.

Hurst, S. A., y Mauron, A. (2003). Assisted suicide and euthanasia in Switzerland: allowing a role for non-physicians. *BMJ*, *326*(7383), 271–273.

Husserl, E. (1997) *Ideas relativas a una fenomenología pura y una filosofía fenomenológica. Libro II: Investigaciones fenomenológicas sobre la constitución.* (Trad. Antonio Zirión) México D.F.: Universidad Nacional Autónoma de México.

Illich, I. (1976). *Medical Nemesis: The expropiation of health*. London: Alder and Boyars.

Ivanović, N., Büche, D., y Fringer, A. (2014). Voluntary stopping of eating and drinking at the end of life - a “systematic search and review” giving insight into an option of hastening death in capacitated adults at the end of life. *BMC Palliative Care*, *13*(1). doi: 10.1186/1472-684X-13-1

Jacelon, C. S. (2003). The Dignity of Elders in an Acute Care Hospital. *Qualitative Health Research*, *13*(4), 543–556. doi: 10.1177/1049732302250762

Jacobson, N. (2009a). A taxonomy of dignity: a grounded theory study. *BMC International Health and Human Rights*, *9*, 3. doi: 10.1186/1472-698X-9-3

Jacobson, N. (2009b). Dignity violation in health care. *Qualitative Health Research*, *19*(11), 1536–1547. doi: 10.1177/1049732309349809

Jansen, L. A. (2015). Voluntary Stopping of Eating and Drinking (VSED), Physician-Assisted Suicide (PAS), or Neither in the Last Stage of Life?

PAS: No; VSED: It Depends. *Annals of Family Medicine*, *13*, 410–411.

Jaspers, K. (1959). Las acciones incondicionadas que rebasan la existencia empírica. En *Filosofía, Clarificación de la existencia* (pp. 63–130). Revista de Occidente.

Jiménez Aboitiz, R. (2012). *¿De la muerte (de)megada a la muerte reivindicada? Análisis de la muerte en la sociedad española actual: muerte sufrida, muerte vivida y discursos sobre la muerte* (tesis doctoral). Universidad de Valladolid.

Johnson, P. R. (1998). An analysis of “dignity”. *Theoretical Medicine and Bioethics*, *19*(4), 337–352.

Jonas, H. (1992). Herramienta, imagen y tumba. Lo transanimal en el ser humano. En *Pensar sobre Dios y otros ensayos* (pp. 39–55). Barcelona: Herder.

Jordan, M. C. (2010). Bioethics and “human dignity”. *The Journal of Medicine and Philosophy*, *35*(2), 180–196. doi: 10.1093/jmp/jhq010

Jors, K., Adami, S., Xander, C., Meffert, C., Gaertner, J., Bardenheuer, H., Buchheidt, D., Mayer-Steinacker, R., Viehrig, M, George, W., y Becker, G. (2014). Do the circumstances allow for a dignified death? *Cancer*, *120*(20), 3254–3260. doi: 0.1002/cncr.28702

Juan Pablo II. (1984). Carta apostólica Salvifi Doloris. Acceso 23 2017. Disponible en: http://www.vatican.va/roman_curia/pontifical_councils/hlthwork/documents/hf_jp-ii_apl_11021984_salvifici-doloris_sp.html

Kade, W. (2000). Death with Dignity: A Case Study.

Kant, I. (2002). *Fundamentación para una metafísica de las costumbres*. (trad. Roberto R. Aramayo) Madrid: Alianza Editorial.

Karel, M. J. (2000). The Assessment of values in medical decision making. *Journal of Aging Studies*, *14*(4), 403–422.

Kass, L. R. (1990). Death with dignity and the sanctity of life. *Commentary*, *89*(3), 33–34.

Kass, L. R. (1993). Is there a right to die? *Hastings Center Report*, *23*(1), 34–43.

Kaufman, S. R. (2000). In the Shadow of “Death with Dignity”: Medicine and Cultural Quandaries of the Vegetative State. *American Anthropologist*, *102*(1), 69–83.

Keenan, J. F. (1996). The Concept of Sanctity of Life and its use in Contemporany Bioethical Discussion. En K. Bayertz (Ed.), *Sanctity of life and human dignity*. Dordrecht: Kluwer Academic Pulishers.

Kellehear, A. (2007). *A Social History of Dying*. Cambridge: Cambridge University Press.

Kelly, B., Burnett, P., Pelusi, D., Badger, S., Varghese, F., y Robertson, M. (2002). Terminally ill cancer patients’ wish to hasten death. *Palliative Medicine*, *16*, 339–345. doi: 10.1191/ 0269216302pm538oa

Kissane, D. W., Clarke, D. M., y Street, A. F. (2001). Demoralization syndrome--a relevant psychiatric diagnosis for palliative care. *Journal of Palliative Care*, *17*(1), 12–21.

Kleinman, A. (1988). *The illness narratives: Suffering, healing, and the human condition*. New York: Basic Books.

Kuhse, H. (1981). Debate: Extraordinary means and the sanctity of life. *Journal of Medical Ethics*, *7*, 74–82.

Latimer, E. (1991). Caring for seriously ill and dying patients: the philosophy and ethics. *Canadian Medical Association Journal*, *144*(7), 859–867.

Lavery, J. V., Boyle, J., Dickens, B. M., Maclean, H., y Singer, P. A. (2001). Origins of the desire for euthanasia and assisted suicide in people with HIV-1 or AIDS: A qualitative study. *Lancet*, *358*(9279), 362–367.

Lavoie, M., Blondeau, D., y Picard-Morin, J. (2011). The Autonomy Experience of Patients in Palliative Care. *Journal of Hospice and Palliative Nursing*, *13*(1), 47–53. doi: 10.1097/NJH.0b013e318202425c

Le Breton, D. (1999). *Antropología del dolor* (1ª ed.). Barcelona: Seix Barral.

Leder, D. (1990). *The Absent body*. Chicago: University of Chicago Press.

Lee, M. a, Nelson, H. D., Tilden, V. P., Ganzini, L., Schmidt, T. A, y Tolle, S. W. (1996). Legalizing assisted suicide--views of physicians in Oregon. *The New England Journal of Medicine*, *334*(5), 310–315. doi: 10.1056/NEJM199602013340507

Leung, D. (2007). Granting death with dignity: patient, family and professional perspectives. *International Journal of Palliative Nursing*, *13*(4), 170–175.

Li, H.-C., Richardson, A., Speck, P., y Armes, J. (2014). Conceptualizations of dignity at the end of life: exploring theoretical and cultural congruence with dignity therapy. *Journal of Advanced Nursing*. doi: 10.1111/jan.12455

Luper, S. (2014). *The Cambridge Companion to Life and Death*. New York: Cambridge University Press.

MacIntyre, A. C. (2001). *Tras la virtud*. Barcelona: Crítica.

Macklin, R. (2003). Dignity is a useless concept. *BMJ*, *327*(7429), 1419–1420. doi: 10.1136/bmj.327.7429.1419

Mak, Y. Y. W., y Elwyn, G. (2005). Voices of the terminally ill: uncovering the meaning of desire for euthanasia. *Palliative Medicine*, *19*(1), 343–350.

Martina M., J. F. (s.f). Historia de la anestesia. Acceso 15 April 2017. Disponible en: http://www.csen.com/historia.pdf

Martínez, M., Arantzamendi, M., Belar, A., Carrasco, J. M., Carvajal, A., Rullán, M., y Centeno, C. (2016). “Dignity therapy”, a promising intervention in palliative care: A comprehensive systematic literature review. *Palliative Medicine.* doi: 10.1177/0269216316665562

Materstvedt, L. J. (2015). Caring and killing in the clinic: the argument of self-determination. En K. Ohnsorge, H. Gudat, y C. Rehmann-Sutter (Eds.), *The Patient's Wish to Die. Research, Ethics and Palliative Care.* Oxford: Oxford University press.

McGrath, P. (1998). Autonomy, discourse, and power: a postmodern reflection on principlism and bioethics. *The Journal of Medicine and Philosophy*, *23*(5), 516–532. doi: 10.1076/jmep.23.5.516.2568

McNamara, B. (2004). Good enough death: autonomy and choice in Australian palliative care. *Social Science and Medicine*, *58*(5), 929–938. doi: 10.1016/j.socscimed.2003.10.042

Merriam Webster. (2013). Webster's International Dictionary. Acceso 24 Mato 2017). Disponible en: https://www.merriam-webster.com/dictionary/dignity

Mesler, M. A, y Miller, P. J. (2000). Hospice and assisted suicide: the structure and process of an inherent dilemma. *Death Studies*, *24*(2), 135–155.

Miller, P. J. (2000). Life after death with dignity: The Oregon Experience. *Social Work*, *45*(3), 263–271.

Monforte-Royo, C., Porta-Sales, J., Balaguer, A. (2016). The wish to hasten death: Reflections from practice and research, *Nursing Ethics, 23*(5):587-589 1–7. doi: 10.1177/0969733015576359

Monforte-Royo, C., Villavicencio-Chávez, C., Tomás-Sábado, J., y Balaguer, A. (2011). The wish to hasten death: a review of clinical studies. *Psycho-Oncology*, *20*(8), 795–804. doi: 10.1002/pon.1839

Monforte-Royo, C., Villavicencio-Chávez, C., Tomás-Sábado, J., Mahtani-Chugani, V., y Balaguer, A. (2012). What lies behind the wish to hasten death? A systematic review and meta-ethnography from the perspective of patients. *PloS One*, *7*(5), e37117. doi: 10.1371/journal.pone.0037117

Montero, E. (2013). *Cita con la muerte. 10 años de eutanasia legal en Bélgica*. Madrid: Ediciones Rialp.

Morin, E. (1994). *El hombre y la muerte* (6ª ed.). Barcelona: Kairós.

Morris, D. B. (1991). *The culture of pain* (1ª ed.). Oakland: University of California Press.

National Institutes of Health. (1979). *The Belmont Report Ethical Principles and Guidelines for the Protection of Human Subjects of Research*.

Nilmanat, K., Promnoi, C., Phungrassami, T., Chailungka, P., Tulathamkit, K., Noo-urai, P., y Phattaranavig, S. (2015). Moving Beyond Suffering: the Experiences of Thai Persons With Advanced Cancer. *Cancer Nursing*, *38*(3), 224–231. doi: 10.1097/NCC.0000000000000169

Nissim, R., Gagliese, L., y Rodin, G. (2009). The desire for hastened death in individuals with advanced cancer: A longitudinal qualitative study. *Social Science and Medicine*, *69*(2), 165–171. doi: 10.1016/j.socscimed.2009.04.021

Noblit, G., y Hare, R. (1988). *Meta-ethnography: Sinthesizing qualitative studies*. Newbury Park: Sage.

Nordenfelt, L. (2004). The varieties of dignity. *Health Care Analysis*, *12*(2), 69–81. doi: 10.1023/B:HCAN.0000041183.78435.4b

Nordgren, S., y Fridlund, B. (2001). Patients' perceptions of self-determination as expressed in the context of care. *Journal of Advanced Nursing*, *35*(1), 117–125.

Ohnsorge, K. (2015). *Investigations in Hermeneutic Bioethics* (Doctoral thesis). Vrije Universiteit.

Ohnsorge, K., Gudat, H., y Rehmann-Sutter, C. (2014). What a wish to die can mean: reasons, meanings and functions of wishes to die, reported from 30 qualitative case studies of terminally ill cancer patients in palliative care. *BMC Palliative Care*, *13*(38). doi: 10.1186/1472-684X-13-38

Ohnsorge, K., Gudat, H., y Rehman-Sutter, C. (2014). Intentions in wishes to die: analysis and a typology – A report of 30 qualitative case studies of terminally ill cancer patients in palliative care. *Psycho-Oncology*. doi: 10.1002/pon

Ohnsorge, K., Keller, H., Widdershoven, G., y Rehmann-Sutter, C. (2012). Ambivalence'at the end of life How to understand patients' wishes ethically. *Nursing Ethics*, *19*(5), 629–641. doi: 10.1177/0969733011436206

Onwuteaka-philipsen, B. D., Heide, A. Van Der, Koper, D., Keij-deerenberg, I., y Rietjens, J. A. C. (2003). Public health Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995, and 2001. *The Lancet*, *632*(9381), 395–399.

Östlund, U., Brown, H., y Johnston, B. (2012). Dignity conserving care at end-of-life: a narrative review. *European Journal of Oncology Nursing*, *16*(4), 353–367. doi: 10.1016/j.ejon.2011.07.010

Pannuti, F., y Tanneberger, S. (1993). Dying with dignity: illusion, hope or human right?. *Relation*, *14*(2), 172–173.

Parens, E. (2013). On good and bad forms of medicalization. *Bioethics*, *27*(1), 28–35. doi: 10.1111/j.1467-8519.2011.01885.x

Paterson, B. L. (2001). The shifting perspectives model of chronic illness. *Journal of Nursing Scholarship*, *33*(1), 21–26.

Paterson, B. L., Thorne, S. E., Cannam, C., y Jillings, C. (2001). *Meta-study of qualitative health research. A practical guide to meta-analysis and meta-synthesis.* Thousand Oaks: SAGE Publications.

Pearlman, R. A., Hsu, C., Starks, H., Back, A. L., Gordon, J. R., Bharucha, A. J., Koenig, B. A., y Battin, M. P. (2005). Motivations for physician-assisted suicide. *Journal of General Internal Medicine*, *20*(3), 234–239. doi: 10.1111/j.1525-1497.2005.40225.x

Periyakoil, V. S., Kraemer, H. C., y Noda, A. (2009). Creation and the Empirical Validation of the Dignity Card-Sort Tool To Assess Factors Influencing Erosion of Dignity at Life's End. *Journal of Palliative Medicine*, *12*(12), 1125–1130. doi: 10.1089=jpm.2009.0123

Periyakoil, V. S., Noda, A. M., y Kraemer, H. C. (2010). Assessment of Factors Influencing Preservation of Dignity at Life's End: Creation and the Cross-Cultural Validation of the Preservation of Dignity Card-Sort Tool. *Journal of Palliative Medicine*, *13*(5), 495–500.

Periyakoil, V. S., Stevens, M., y Kraemer, H. (2013). Multicultural long-term care nurses' perceptions of factors influencing patient dignity at the end of life. *Journal of the American Geriatrics Society*, *61*(3), 440–446. doi: 10.1111/jgs.12145

Pernick, M. S. (1999). Brain Death in a Cultural Context: The Reconstruction of Death, 1967-1981. En S. J. Yougner, R. M. Arnorld, y R. Schapiro (Eds.), *The Definition of Death: Contemporary Controversies*. Baltimore and London: JHU Press.

Pestinger, M., Stiel, S., Elsner, F., Widdershoven, G., Voltz, R., Nauck, F., y Radbruch, L. (2015). The desire to hasten death: Using Grounded Theory for a better understanding "When perception of time tends to be a slippery slope." *Palliative Medicine*, *29*(8), 711–719. doi: 10.1177/0269216315577748

Pfänder, A. (2007). *Fenomenología de la voluntad*. Madrid: Avarigani.

Pico della Mirandola, G. (2003). *Discurso sobre la dignidad del hombre*. México D.F.: Universidad Nacional Autónoma de México.

Pleschberger, S. (2007). Dignity and the challenge of dying in nursing homes: The residents' view. *Age and Ageing*, *36*(2), 197–202. doi: 10.1093/ageing/afl152

Pope, C., Mays, N., y Popay, J. (2007). *Synthesising qualitative and quantitative health evidence: A guide to methods*. Berkshire: Open University Press. McGraw-Hill Education.

Potter, V. R. (1971). *Bioethics: Bridge to the Future*. Englewood Cliffs: Prentice

Hall Publisher.

President’s Council on Bioethics. (2008). *Human dignity and Bioethics. Essays Commissioned by the President’s Council on Bioethics*. Washington, D.C.

Public Health Division. (2017). Oregon’s Death with Dignity Act. Acceso 11 Abril 2017. Disponible en: https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf

Pullman, D. (1996). Dying with Dignity and the Death of Dignity. *Health Law Journal*, *4*, 197–219.

Pullman, D. (2004). Death, dignity, and moral nonsense. *Journal of Palliative Care*, *20*(3), 171–178.

Quill, T. E (1991). Death and dignity-A case of individual Decision Making. *The New England Journal of Medicine*, *324*(10), 691–694.

Quill, T. E (2015). Voluntary stopping of eating and drinking (VSED), physician-assisted death (PAD), or neither in the last stage of life? Both should be available as a last resort. *Annals of Family Medicine*, *13*(5), 408–409. doi: 10.1370/afm.1850

Real Academia Española (2014a). Diccionario de la Real Academia Española de la Lengua. Disponible en: http://dle.rae.es/srv/fetch?id=DlX5ZXZ

Real Academia Española (2014b). Diccionario de la Real Academia Española de la Lengua. Disponible en: http://dle.rae.es/srv/search?m=30&w=alquimia

Rehman-Sutter, C. (2015). End-of-life ethics from the perspectives of patients’ wishes. En C. Rehman-Sutter, H. Gudat, y K. Ohnsorge (Eds.), *The Patient’s Wish to Die. Research, Ethics, and Palliative Care* (1st ed.). Oxford: Oxford University Press.

Rehman-Sutter, C., Gudat, H., y Ohnsorge, K. (2015). Why it is important to know about patients’ wishes to die. En C. Rehman-Sutter, H. Gudat, y K.

Ohnsorge (Eds.), *The Patient’s Wish to Die: Research, Ethics, and Palliative Care* (1st ed.). Oxford: Oxford University Press.

Rendtorff, J. D. (2002). Basic ethical principles in European bioethics and biolaw: autonomy, dignity, integrity and vulnerability--towards a foundation of bioethics and biolaw. *Medicine, Health Care, and Philosophy*, *5*(3), 235–244. doi: 10.1023/A:1021132602330

Requena Meana, P. (2008). Dignidad y autonomía en la bioética norteamericana. *Cuadernos de Bioética*, *19*(66), 255–270.

Robinson, S., Kissane, D. W., Brooker, J., Hempton, C., y Burney, S. (2017). The Relationship Between Poor Quality of Life and Desire to Hasten Death: A Multiple Mediation Model Examining the Contributions of Depression, Demoralization, Loss of Control, and Low Self-worth. *Journal of Pain and Symptom Management*, *53*(2), 243–249.

Rodin, G., Lo, C., Mikulincer, M., Donner, A., Gagliese, L., y Zimmermann, C. (2009). Pathways to distress: The multiple determinants of depression, hopelessness, and the desire for hastened death in metastatic cancer patients. *Social Science and Medicine*, *68*(3), 562–569. doi: 10.1016/j.socscimed.2008.10.037

Rodin, G., Zimmermann, C., Rydall, A., Jones, J., Shepherd, F. A., Moore, M., Fruh, M., Donner, A., y Gagliese, L. (2007). The desire for hastened death in patients with metastatic cancer. *Journal of Pain and Symptom Management*, *33*(6), 661–675. doi: 10.1016/j.jpainsymman.2006.09.034

Rodríguez-Prat, A., Balaguer, A., Booth, A., y Monforte-Royo, C. (2017). Understanding patients’ experiences of the wish to hasten death: An updated and expanded systematic review and meta-ethnography [En revisión].

Rodríguez-Prat, A., y Escribano, X. (2017). A philosophical view on the experience of dignity and autonomy through the phenomneology of illness. *Journal of Medicine and Philosophy* [Aceptado 14 febrero].

Rodríguez-Prat, A., y Monforte-Royo, C. (2017). 25 years after Intoxicated by My Illness. Challenges for Medical Humanities. *Lancet*, *389*(10066), 249–250.

Rodríguez-Prat, A., Monforte-Royo, C., Porta-Sales, J., Escribano, X., y Balaguer, A. (2016). Patient Perspectives of Dignity, Autonomy and Control at the End of Life: Systematic Review and Meta-Ethnography. *PLoS ONE*, *11*(3), e0151435. doi: 10.1371/journal.pone.0151435

Rodríguez-Prat, A., y van Leeuwen, E. (2017). Assumptions and moral understanding of the wish to hasten death: a philosophical review of qualitative studies [En revisión].

Ruhnke, G. W., Wilson, S. R., y Akamatsu, T. (2000). Ethical Decision Making and Patient Autonomy. A Comparison of Physicians and Patients in Japan and the United States. *Ethics in Cardiopulmonary Medicine*, *118*(4), 1172–1182.

Rullán, M., Carvajal, A., Núñez-Córdoba, J. M., Martínez, M., Carrasco, J. M., García, I., Arantzamendi, M., Belar, A., y Centeno, C. (2015). Spanish Version of the Patient Dignity Inventory: Translation and Validation in Patients with Advanced Cancer. *Journal of Pain and Symptom Management*, *50*(6), 874–881.e1. doi: 10.1016/j.jpainsymman.2015.07.016

Sampaio, L. (1992). To die with dignity. *Social Science and Medicine*, *35*(4), 433–441.

Sandelowski, M., y Barroso, J. (2006). *Handbook for synthesizing qualitative research*. New York: Springer Publishing Company.

Sartre, J.-P. (1993). *El ser y la nada* [Trad.: Juan Valmar]. Barcelona: Altaya.

Saunders, C. (1965). The last stages of life. *American Journal of Nursing*, *65*(3), 70–75.

Schicktanz, S., Raz, A., y Shalev, C. (2010). The cultural context of patient’s autonomy and doctor’s duty: passive euthanasia and advance directives in

Germany and Israel. *Medicine, Health Care, and Philosophy*, *13*(4), 363–369. doi: 10.1007/s11019-010-9262-3

Schrag, C. (1982). Being in pain. En V. Kestenbaum (Ed.), *The Humanity of the ill* (pp. 101–124). Knoxville: University of Tennessee Press.

Schroepfer, T. A. (2006). Mind Frames Towards Dying and Factors Motivating Their Adoption by Terminally Ill Elders. *Journal of Gerontology*, *61*(3), 129–140.

Schroepfer, T. A. (2008). Social relationships and their role in the consideration to hasten death. *The Gerontologist*, *48*(5), 612–621.

Schroepfer, T. A., Noh, H., y Kavanaugh, M. (2009). The myriad strategies for seeking control in the dying process. *The Gerontologist*, *49*(6), 755–766. doi: 10.1093/geront/gnp060

Schumacher, B. N. (2011). *Death and Mortality in Contemporary Philosophy*. New York: Cambridge University Press.

Seifert. Josef. (1995). El hombre como persona en el cuerpo. Qué significa ‘ser una persona’. *Espíritu. Cuadernos Del Instituto Filosófico de Balmesiana*, *112*, 129–156.

Shell, S. M. (2008). Kant’s Concept of Human Dignity as a Resource for Bioethics. En *Human dignity and Bioethics. Essays Commissioned by the President’s Council on Bioethics*. Washington, D.C.

Singer, P. (1983). Sanctity of Life or Quality of Life? *Pediatrics*, *72*(1), 128–129.

Singer, P., y Kuhse, H. (1988). Resolving arguments about the sanctity of life: a response to Long. *Journal of Medical Ethics*, *14*, 198–199.

Singer, P., y Kuhse, H. (2003). *Desacralizar la vida humana*. Madrid: Cátedra.

Smoot, W. (1977). The Social Dimension of Death-Anxiety. *Philosophy Today*, *21*(1), 84–89. doi: 10.5840/philtoday197721143

Steinhauser, K. E., Christakis, N. A, Clipp, E. C., McNeilly, M., McIntyre, L., y

Tulsky, J. A. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*, *284*(19), 2476–2482.

Stiel, S., Pestinger, M., Moser, A., Widdershoven, G., Lüke, U., Meyer, G., Voltz, R., Nauck, F., y Radbruch, L. (2010). The Use of Grounded Theory in Palliative Care: Methodological Challenges and Strategies. *Palliative Medicine*, *13*(8), 997–1003. doi: 10.1089/jpm.2010.0050

Street, A. F., y Kissane, D. W. (2001). Constructions of dignity in end-of-life care. *Journal of Palliative Care*, *17*(2), 93–101.

Sullivan, A. D., Hedberg, K., y Fleming, D. W. (2000). Legalized physician-assisted suicide in Oregon—the second year. *The New England Journal of Medicine*, *342*(8), 598–604.

Sullivan, a D., Hedberg, K., y Hopkins, D. (2001). Legalized physician-assisted suicide in Oregon, 1998-2000. *The New England Journal of Medicine*, *344*(8), 605–607. doi: 10.1056/NEJM200102223440811

Sullivan, M. D. (2002). The illusion of patient choice in end-of-life decisions. *The American Journal of Geriatric Psychiatry*, *10*(4), 365–372.

Sulmasy, D. P. (2005). Death, Dignity, and the Theory of Value. *Ethical Perspectives*, *9*(2), 103–130. https://doi.org/10.2143/EP.9.2.503850

Sulmasy, D. P. (2013). The varieties of human dignity: a logical and conceptual analysis. *Medicine, Health Care, and Philosophy*, *16*(4), 937–944. https://doi.org/10.1007/s11019-012-9400-1

Sundström, P. (2001). Disease: The phenomenological and conceptual center of practical-clinical medicine. En S. K. Toombs (Ed.), *Handbook of Phenomenology and Medicine* (pp. 109–126). Dordrecht: Kluwer Academic Publishers.

Taylor, C. (1992). *The sources of the self. The Making of the Modern Identity*. Cambridge: Cambridge University Press.

Taylor, C. (1994). *Ética de la autenticidad*. Barcelona: Paidós.

Taylor, C. (2005). *La libertad de los modernos*. Madrid: Amorrortu Editores.

Thielicke, H. (1984). *Vivir con la muerte*. Barcelona: Herder.

Thomas, L. V. (1983). *Antropología de la muerte*. México D.F.: Fondo de Cultura Económica.

Tolle, S. W., Tilden, V. R., Drach, L. L., Fromme, E. K., Perrin, N. A, y Hedberg, K. (2004). Characteristics and proportion of dying Oregonians who personally consider physician-assisted suicide. *The Journal of Clinical Ethics*, *15*(2), 111–118.

Tolstoi, L. (1995). *La muerte de Ivan Illich*. Madrid: Alianza.

Toombs, S. K. (1988). Illness and the paradigm of the lived body. *Theoretical Medicine and Bioethics*, *9*(2), 201–226.

Toombs, S. K. (1990). The temporality of illness: Four levels of experience. *Theoretical Medicine*, *11*(3), 227–241. doi: 10.1007/BF00489832

Toombs, S. K. (1992). *The meaning of illness: a phenomenological account of the different perspectives of physician an patient*. Boston: Kluwer Academic.

Toombs, S. K. (Ed.) (2001). *Handbook of phenomenology in medicine*. Dordrecht: Kluwer Academic Publishers.

Toombs, S. K. (2004). Living and dying with dignity: reflections on lived experience. *Journal of Palliative Care*, *20*(3), 193–200.

Tuten, M. (2001). A Death With Dignity in Oregon. *Oncology Nursing Forum*, *28*(1), 58.

Organización de las Naciones Unidas. Declaración Universal de los Derechos Humanos (1948). Acceso 24 Mayo 1017. Disponible en: http://www.un.org/es/documents/udhr/index_print.shtml

Van Brussel, L. (2014). Autonomy and dignity: a discussion on contingency and dominance. *Health Care Analysis*, *22*(2), 174–191. doi: 10.1007/s10728-012-0217-0

van Wijngaarden, E., Leget, C., y Goossensen, A. (2015). Ready to give up on life: The lived experience of elderly people who feel life is completed and no longer worth living. *Social Science & Medicine*, *138*, 257–264. doi: 10.1016/j.socscimed.2015.05.015

Vehling, S., y Mehnert, A. (2014). Symptom burden, loss of dignity, and demoralization in patients with cancer: a mediation model. *Psycho-Oncology*, *23*(3), 283–290. doi: 10.1002/pon.3417

Vig, E. K., y Pearlman, R. A. (2004). Good and bad dying from the perspective of terminally ill men. *Archives of Internal Medicine*, *164*(9), 977–981. doi: 10.1001/archinte.164.9.977

Villavicencio-Chávez, C., Monforte-Royo, C., Tomás-Sábado, J., Maier, M. A., Porta-Sales, J., y Balaguer, A. (2014). Physical and psychological factors and the wish to hasten death in advanced cancer patients. *Psycho-Oncology*, *23*, 1125–1132. doi: 10.1002/pon.3536

Vladeck, B. C., y Westphal, E. (2012). Dignity-driven decision making: a compelling strategy for improving care for people with advanced illness. *Health Affairs*, *31*(6), 1269–1276. doi: 10.1377/hlthaff.2012.0173

Vlug, M. G., de Vet, H. C. W., Pasman, H. R. W., Rurup, M. L., y Onwuteaka-Philipsen, B. D. (2011). The development of an instrument to measure factors that influence self-perceived dignity. *Journal of Palliative Medicine*, *14*(5), 578–586. doi: 10.1089/jpm.2010.0513

Volker, D. L. (2001). Oncology nurses' experiences with requests for assisted dying from terminally ill patients with cancer. *Oncology Nursing Forum*, *28*(1), 39–49.

Volker, D. L., Kahn, D., y Penticuff, J. H. (2004a). Patient Control and End-of-Life Care. Part I: The Advanced Practice Nurse Perspective. *Oncology*

Nursing Forum, *31*(5), 954–960.

Volker, D. L., Kahn, D., y Penticuff, J. H. (2004b). Patient Control and End-of-Life Care Part II: The Patient Perspective. *Oncology Nursing Forum*, *31*(5), 954–960.

Walsh, K., y Kowanko, I. (2002). Nurses’ and patients’ perceptions of dignity. *International Journal of Nursing Practice*, *8*(3), 143–151.

Walter, T. (1994). *The revival of death*. London; New York: Routledge.

White, M., y Callahan, D. (2000). Oregon’s first year: The medicalization of control. *Psychology, Public Policy, and Law*, *6*(2), 331–341. doi: 10.1037//1076-8971.6.2.331

Wilson, F., Ingleton, C., Gott, M., y Gardiner, C. (2014). Autonomy and choice in palliative care: time for a new model? *Journal of Advanced Nursing*, *70*(5), 1020–1029. doi: 10.1111/jan.12267

Wilson, K. G., Chochinov, H. M., McPherson, C. J., Skirko, M. G., Allard, P., Chary, S., Gagnon, P. R., Macmillan, K., De Luca, M., O'Shea, F., Kuhl, D., Fainsinger, R. L., Karam, A., M., y Clinch, J. J. (2007). Desire for euthanasia or physician-assisted suicide in palliative cancer care. *Health Psychology*, *26*(3), 314–323. doi: 10.1037/0278-6133.26.3.314

Winzelberg, G. S., Hanson, L. C., y Tulsky, J. A. (2005). Beyond autonomy: diversifying end-of-life decision-making approaches to serve patients and families. *Journal of the American Geriatrics Society*, *53*(6), 1046–1050. https://doi.org/10.1111/j.1532-5415.2005.53317.x

Wrathall, M y Malpas, J. (Eds.) (2000), *Heidegger, Authenticity, and Modernity. Essays in Honor if Hubert L. Dreyfus. Volume 1*. Cambridge: Massachusetts Institute of Technology Press.

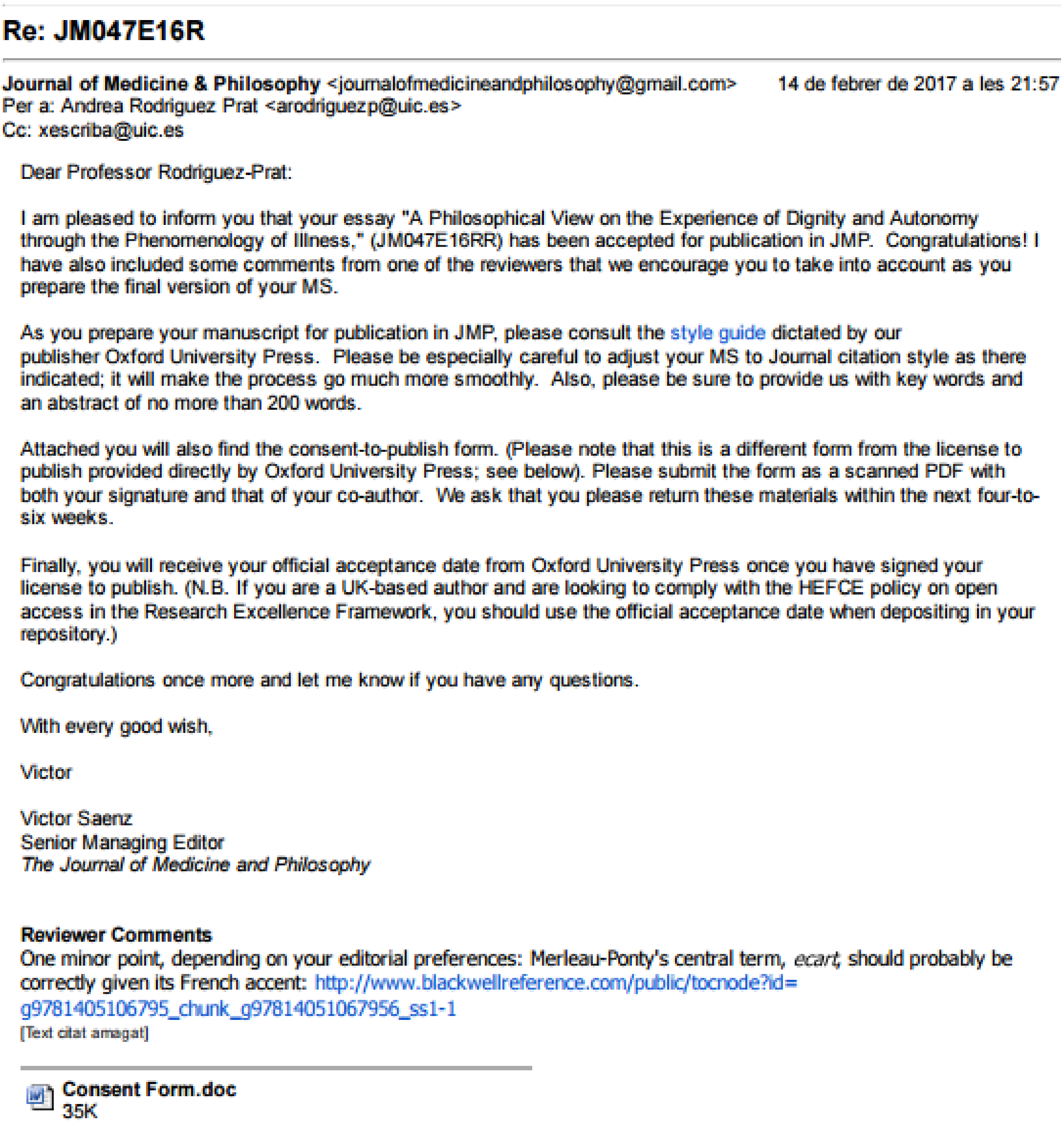
Youngner, S. J., Arnold, R. M., y Schapiro, R. (1999). *The Definition of Death: Contemporary Controversies*. Baltimore and London: JHU Press.

Zaner, R. M. (1971). *The Problem of embodiment: some contributions to a* *phenomenology of the body* (2ª ed.). La Haye: Martinus Nijhoff.

Zimmerman, M. E. (2000). The End of Authentic Selfhood in the Postmodern Age? En M. Wrathall y J. Malpas (Eds.), *Heidegger, Authenticity, and Modernity. Essays in Honor of Hubert L. Dreyfus*. Cambridge; London: The MIT Press.

Anexos

Anexo 1. Correo electrónico de aceptación del segundo artículo de esta tesis



Re: JM047E16R

Journal of Medicine & Philosophy <journalofmedicineandphilosophy@gmail.com> 14 de febrer de 2017 a les 21:57
Per a: Andrea Rodriguez Prat <arodriguezp@uic.es>
Cc: xescriba@uic.es

Dear Professor Rodriguez-Prat:

I am pleased to inform you that your essay "A Philosophical View on the Experience of Dignity and Autonomy through the Phenomenology of Illness," (JM047E16RR) has been accepted for publication in JMP. Congratulations! I have also included some comments from one of the reviewers that we encourage you to take into account as you prepare the final version of your MS.

As you prepare your manuscript for publication in JMP, please consult the style guide dictated by our publisher Oxford University Press. Please be especially careful to adjust your MS to Journal citation style as there indicated; it will make the process go much more smoothly. Also, please be sure to provide us with key words and an abstract of no more than 200 words.

Attached you will also find the consent-to-publish form. (Please note that this is a different form from the license to publish provided directly by Oxford University Press; see below). Please submit the form as a scanned PDF with both your signature and that of your co-author. We ask that you please return these materials within the next four-to-six weeks.

Finally, you will receive your official acceptance date from Oxford University Press once you have signed your license to publish. (N.B. If you are a UK-based author and are looking to comply with the HEFCE policy on open access in the Research Excellence Framework, you should use the official acceptance date when depositing in your repository.)

Congratulations once more and let me know if you have any questions.

With every good wish,

Victor

Victor Saenz
Senior Managing Editor
The Journal of Medicine and Philosophy

Reviewer Comments
One minor point, depending on your editorial preferences: Merleau-Ponty's central term, *ecart*, should probably be correctly given its French accent: http://www.blackwellreference.com/public/tocnode?id=g9781405106795_chunk_g97814051067956_ss1-1
[Text citat amagat]

Consent Form.doc
35K

Anexo 2. Hoja de aceptación del proyecto competitivo Recercaixa 2015

recerCaixa
Avancem amb la ciència
ACUP
Obra Social "la Caixa"

Barcelona, 8 de gener de 2016

Benvolguda Dra. Monforte,

Ens plau informar-vos que el projecte ***Sufrimiento al final de la vida: Comprender para aliviar. (Dignidad percibida, deseo de control y deseo adelantar la muerte en pacientes con cáncer avanzado)*** que vàreu presentar a la convocatòria d'ajuts a la recerca RecerCaixa 2015, ha estat un dels seleccionats per a rebre ajut econòmic. L'import total de l'ajut previst per al vostre projecte és de **69.784€**.

Ens agradaria traslladar-vos la nostra més sincera felicitació en nom de **RecerCaixa, un programa impulsat per l'Obra Social "la Caixa" amb la col·laboració de l'ACUP**.

La convocatòria 2015 de RecerCaixa ha estat molt competitiva. S'han presentat 221 projectes d'elevada qualitat científica, que han estat avaluats per diferents panells d'experts coordinats i dirigits per l'AGAUR i ratificats per una comissió conjunta Obra Social "la Caixa" – ACUP.

S'han seleccionat dinou projectes, valorats pels experts com de màxima qualitat des del punt de vista científic i que, alhora, s'adeqüen a les finalitats de la convocatòria. El vostre ha estat un d'aquests dinou projectes. Enhorabona.

Aquesta notificació és confidencial, us demanem que no la feu pública. RecerCaixa durà a terme els tràmits necessaris per fer públics els resultats de la convocatòria 2015.

En cas que tingueu algun dubte o vulgueu comunicar-vos amb nosaltres, ho podeu fer escrivint a info@recercaixa.cat o bé trucant al telèfon 93.581.72.17 (Sra. Alba Morales) o 93 519 46.70 (Sra. Vanessa Silvano).

Ben cordialment,

Jordi Portabella
Director de l'Àrea de
Recerca i Coneixement,
Obra Social "la Caixa"

Josep Joan Moreso
Director del Programa
RecerCaixa

Enric Fossas
President de l'ACUP

Anexo 3. Hoja del consentimiento informado del proyecto de Recercaixa

ESTUDIO "Dignidad percibida, deseo de control y deseo de adelantar la muerte en pacientes oncológicos"

Apreciado Sr/a:

Nos gustaría invitarles a participar en el estudio "Dignidad percibida, deseo de control y deseo de adelantar la muerte en pacientes oncológicos".

El objetivo del estudio es conocer los factores relacionados con la vivencia o deseo de control en pacientes oncológicos. El beneficio del estudio es conocer los factores que puedan ayudar a pacientes que estén en su misma situación, mejorando su calidad de vida a través de la mejora de la comunicación entre los profesionales y los pacientes. También se prevé un beneficio para los profesionales de la salud, que podrán evaluar esos aspectos con escalas adecuadas a tal efecto.

La información para este estudio se obtiene a través de una entrevista que le realizaría la Sra. Andrea Rodríguez Prat, la investigadora principal del proyecto. Ella concretaría con usted un día y hora para que pueda explicarle su experiencia sobre el control y autonomía en el contexto de su enfermedad.

La duración de esta entrevista será de 30-60 minutos. Podría ser que para clarificar algunos aspectos que no hayan quedado claros en la primera entrevista, se le solicite una segunda entrevista que normalmente es de menor duración.

Para posteriormente analizar los datos que usted nos haya proporcionado, la entrevista será grabada en una grabadora. La información grabada es totalmente anónima y confidencial y será destruida una vez haya finalizado el estudio.

La investigadora se hace cargo de que para algunas personas hablar de su experiencia no es fácil, pudiendo generar emoción e incluso malestar al hablar sobre ello. No obstante, la participación en este estudio no conlleva ningún riesgo.

Todos los datos recogidos serán tratados de forma anónima y confidencial y serán eliminados al finalizar el estudio. Los nombres utilizados en la redacción del estudio serán ficticios para asegurar la confidencialidad del participante. Todo ello de acuerdo con la Ley Orgánica 15/1999 de Protección de Datos de Carácter Personal.

Si usted acepta participar en el estudio se le proporcionará un documento de consentimiento informado para que lo firme.

Si deseara más información sobre este estudio contacte con su investigadora principal en los siguientes datos: Andrea Rodríguez Prat. Correo electrónico: arodriguezp@uic.es / Teléfono: 650-517-534

L´Hospitalet de Llobregat, 4 de mayo de 2016

Anexo 4. Hoja de información al paciente del proyecto de Recercaixa

“DIGNIDAD PERCIBIDA, DESEO DE CONTROL Y DESEO DE AELANTAR LA MUERTE EN PACIENTES EN PACIENTES ONCOLÓGICOS”

Código del centro_______ Código del paciente_______

PACIENTE:

He leído y comprendido toda la información que se me ha facilitado y otorgo el consentimiento para permitir mi participación en el estudio: “Dignidad percibida, deseo de control y deseo de adelantar la muerte en pacientes oncológicos”

Nombre y apellidos:

____

Fecha:____/____/2016 Firma:

INVESTIGADOR:

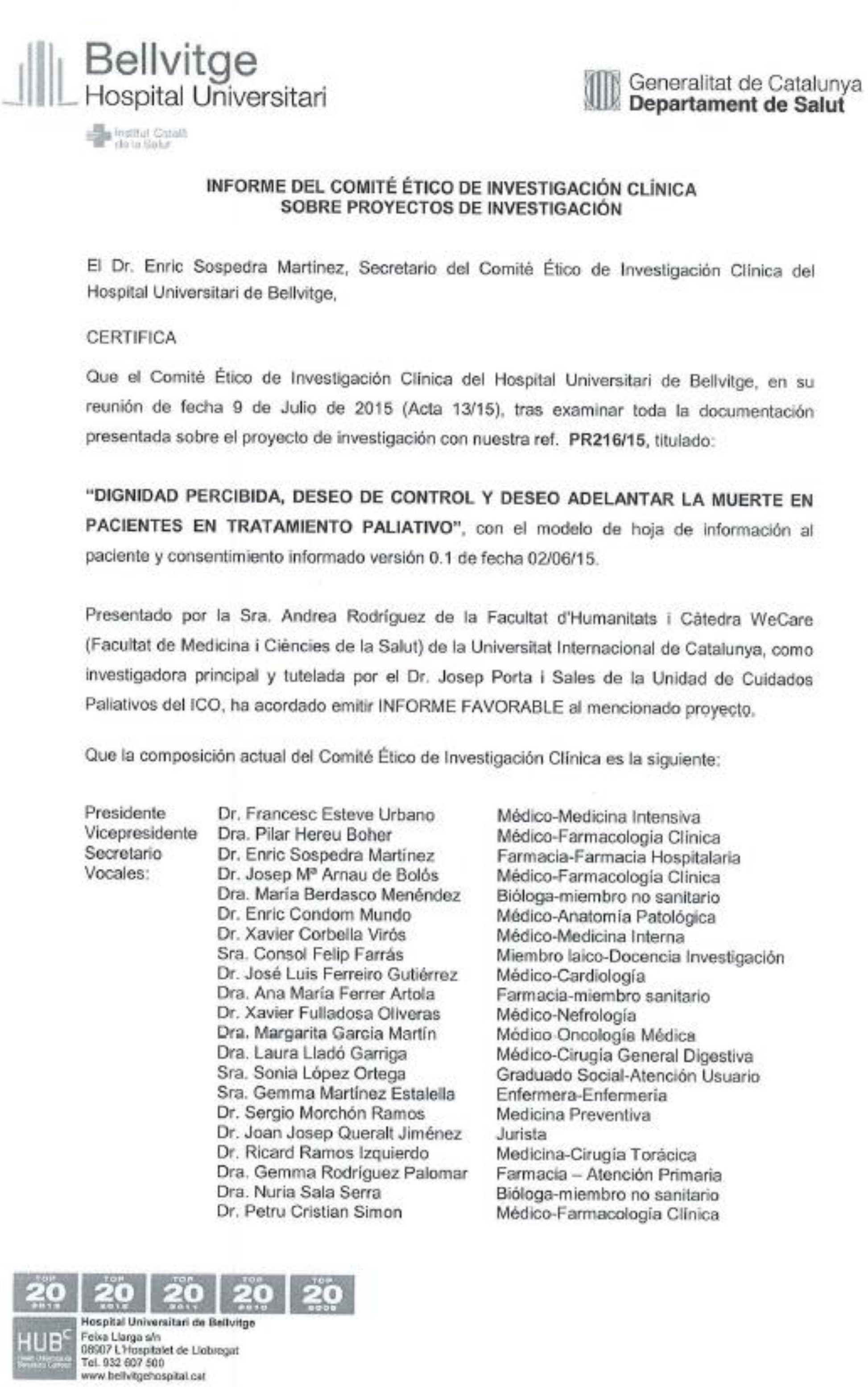
Por la presente declaro que he informado personalmente la naturaleza y objetivos del estudio “DIGNIDAD PERCIBIDA, DESEO DE CONTROL Y DESEO DE AELANTAR LA MUERTE EN PACIENTES ONCOLÓGICOS” al paciente anteriormente mencionado.

Nombre y apellidos:

____

Fecha: ___/____/2016 Firma:

Anexo 5. Documento de aceptación del CEIC de Bellvitge



Bellvitge
Hospital Universitari
Institut Català de la Salut

Generalitat de Catalunya
Departament de Salut

INFORME DEL COMITÉ ÉTICO DE INVESTIGACIÓN CLÍNICA
SOBRE PROYECTOS DE INVESTIGACIÓN

El Dr. Enric Sospedra Martínez, Secretario del Comité Ético de Investigación Clínica del Hospital Universitari de Bellvitge,

CERTIFICA

Que el Comité Ético de Investigación Clínica del Hospital Universitari de Bellvitge, en su reunión de fecha 9 de Julio de 2015 (Acta 13/15), tras examinar toda la documentación presentada sobre el proyecto de investigación con nuestra ref. **PR216/15**, titulado:

"DIGNIDAD PERCIBIDA, DESEO DE CONTROL Y DESEO ADELANTAR LA MUERTE EN PACIENTES EN TRATAMIENTO PALIATIVO", con el modelo de hoja de información al paciente y consentimiento informado versión 0.1 de fecha 02/06/15.

Presentado por la Sra. Andrea Rodríguez de la Facultat d'Humanitats i Càtedra WeCare (Facultat de Medicina i Ciències de la Salut) de la Universitat Internacional de Catalunya, como investigadora principal y tutelada por el Dr. Josep Porta i Sales de la Unidad de Cuidados Paliativos del ICO, ha acordado emitir INFORME FAVORABLE al mencionado proyecto.

Que la composición actual del Comité Ético de Investigación Clínica es la siguiente:

Presidente	Dr. Francesc Esteve Urbano	Médico-Medicina Intensiva
Vicepresidente	Dra. Pilar Hereu Boher	Médico-Farmacologia Clínica
Secretario	Dr. Enric Sospedra Martínez	Farmacia-Farmacia Hospitalaria
Vocales:	Dr. Josep Mª Arnau de Bolós	Médico-Farmacologia Clínica
	Dra. María Berdasco Menéndez	Bióloga-miembro no sanitario
	Dr. Enric Condom Mundo	Médico-Anatomía Patológica
	Dr. Xavier Corbella Virós	Médico-Medicina Interna
	Sra. Consol Felip Farrás	Miembro laico-Docencia Investigación
	Dr. José Luis Ferreiro Gutiérrez	Médico-Cardiología
	Dra. Ana María Ferrer Artola	Farmacia-miembro sanitario
	Dr. Xavier Fulladosa Oliveras	Médico-Nefrología
	Dra. Margarita Garcia Martín	Médico Oncología Médica
	Dra. Laura Lladó Garriga	Médico-Cirugía General Digestiva
	Sra. Sonia López Ortega	Graduado Social-Atención Usuario
	Sra. Gemma Martínez Estalella	Enfermera-Enfermería
	Dr. Sergio Morchón Ramos	Medicina Preventiva
	Dr. Joan Josep Queralt Jiménez	Jurista
	Dr. Ricard Ramos Izquierdo	Medicina-Cirugía Torácica
	Dra. Gemma Rodríguez Palomar	Farmacia – Atención Primaria
	Dra. Nuria Sala Serra	Bióloga-miembro no sanitario
	Dr. Petru Cristian Simon	Médico-Farmacología Clínica

Hospital Universitari de Bellvitge
Feixa Llarga s/n
08907 L'Hospitalet de Llobregat
Tel. 932 607 500
www.bellvitgehospital.cat

Que este Comité cumple la legislación española vigente para este tipo de proyectos, así como las normas ICH y las Normas de Buena Práctica Clínica.

Que en dicha reunión del Comité Ético de Investigación Clínica se cumplió el quórum preceptivo legalmente.

Lo que firmo en L'Hospitalet de Llobregat, a 9 de Julio de 2015

Bellvitge
Hospital Universitari
Comitè Ètic
d'Investigació Clínica

Fdo. Dr. Enric Sospedra Martínez
Secretario del CEIC