

El sufrimiento al final de la vida y el deseo de adelantar la muerte

Cristina Monforte

Cristina Monforte-Royo
Joaquín Tomás-Sábado
Christian Villavicencio-Chávez
Vinita Mahtani-Chugani
Albert Balaguer

Introducción 1

- Creciente interés en analizar el deseo de adelantar la muerte (DAM) en pacientes con procesos avanzados de enfermedad
- Fenómeno que parece afectar a un número considerable de pacientes,
- Especialmente aquellos que se enfrentan a su final ^{1,2,3}

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

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

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

Introducción 2

Hasta ahora, los estudios:

- Etiología multi-factorial del DAM ^{4,5,6}
- Estudios cuantitativos limitan su estudio a un número de variables⁴
- Difícil penetrar en la compleja realidad de la experiencia de un paciente⁴

4. 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: 795-804.

5. Morita T, Tsunoda J, Inoue S, Chihara S (2000) An exploratory factor analysis of existential suffering in Japanese terminally ill cancer patients. *Psychooncology*. 2000; 9: 164-168.

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

Introducción 3

- Necesidad de abordar el significado del DAM desde la realidad del paciente ⁴
- La perspectiva del paciente es esencial
- Estudios cualitativos ayudan a entender los fenómenos ⁷
- Varios estudios analizan el DAM desde una perspectiva cualitativa ^{8,9,10}

4. 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: 795-804.

7. Morse JM, Field PA (1995) *Qualitative research methods for health professionals*: Thousand Oaks, CA: Sage. 272 p.

8. 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.

9. 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.

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

Objetivo

Analizar, a través de una revisión sistemática de Estudios cualitativos primarios, el significado y motivaciones del DAM en pacientes con enfermedad avanzada

Método

Diseño

Revisión sistemática y Síntesis Interpretativa siguiendo el método meta-etnográfico de Noblit & Hare¹⁵

15. Noblit G, Hare R (1988) Meta-ethnography: Synthesizing qualitative studies Newbury Park: Sage.

CRITERIOS DE INCLUSION



- Estudios cualitativos primarios
- Estudios cnetrados en WTHD
- En pacientes con enfermedad avanzada
- Desde la perspectiva o experiencia del paciente
- Estudios de Mixed-Methods
- No límite temporal o de idioma

CRITERIOS DE EXCLUSION



- Estudios en muestras pediátricas
- Estudios cualitativos, pero sin análisis de datos cualitativo

Método:

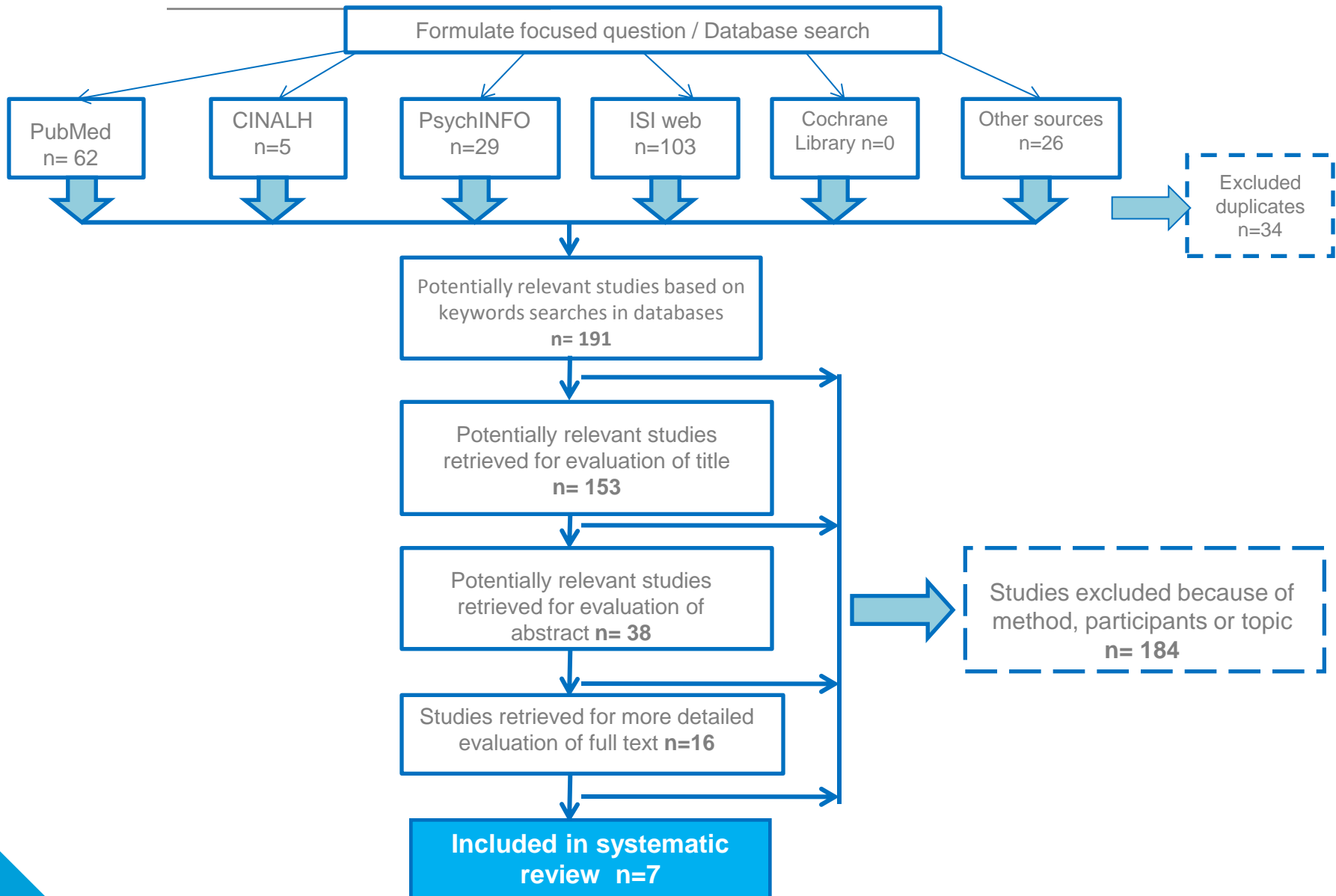
Estrategia de Búsqueda

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

Key to abbreviations as used in Medline (PubMed):

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

Método: Selección de estudios



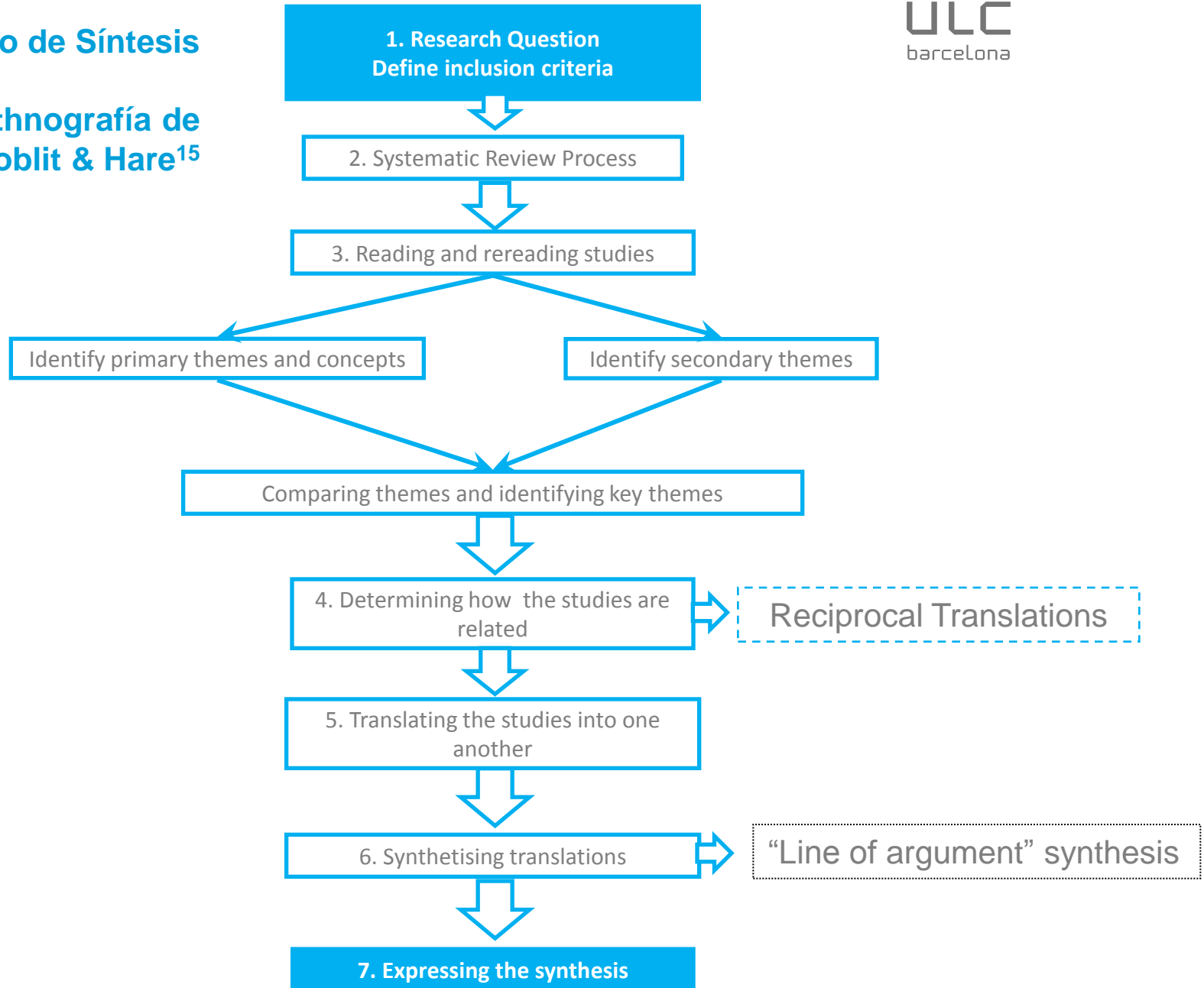
Qualitative Studies Included (n=7)

Quality Assessment: CASP

- Lavery (2001) → Canadá
- Kelly (2002) → Australia
- Coyle (2004) → USA
- Mak (2005) → China
- Pearlman (2005) → USA
- Schroepfer (2006) → USA
- Nissim (2009) → Canadá

Método de Síntesis

Meta-etnografía de Noblit & Hare¹⁵



Traducciones recíprocas

Estudios fueron directamente comparados entre ellos

Traducciones
recíprocas: método
aplicado

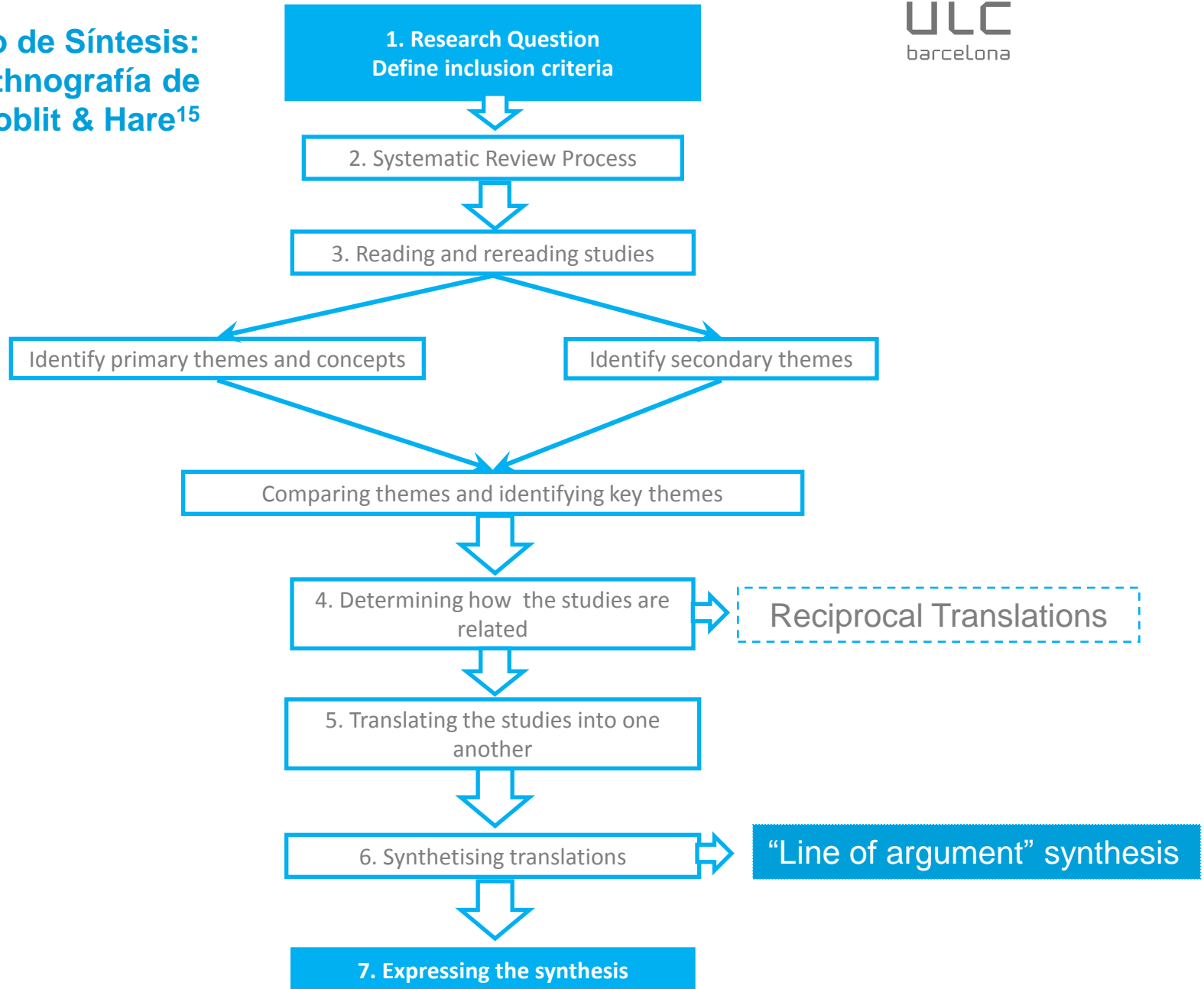
- Identificar temas clave
- Comparación constante de los temas clave en los 7 estudios
- Hallar las categorías finales

Temas identificados en cada estudio

Categories/Subcategories	Study Reference						
	Kelly	Coyle	Lavery	Mak	Nissim	Pearlman	Schroepfer
1. Wish to hasten death in response to physical-psychological-spiritual Suffering	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2. Loss of Self:							
Loss of function	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Loss of control	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sense of 'loss of dignity'	--	Yes	Yes	Yes	Yes	Yes	--
Loss of meaning	Yes	Yes	--	--	Yes	Yes	Yes
3. Fear:							
Fear to dying process	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Fear to imminent death	Yes	Yes	--	Yes	--	--	Yes
4. WTHD: as a desire to live but 'not in this way'; as a sort of 'cry for help'	--	Yes	Yes	Yes	Yes	Yes	Yes
5. WTHD: as a way of ending suffering	Yes	Yes	Yes	Yes	Yes	Yes	Yes
6. WTHD: a kind of control of my life 'to have an ace up one's sleeve'	--	Yes	Yes	--	Yes	Yes	Yes

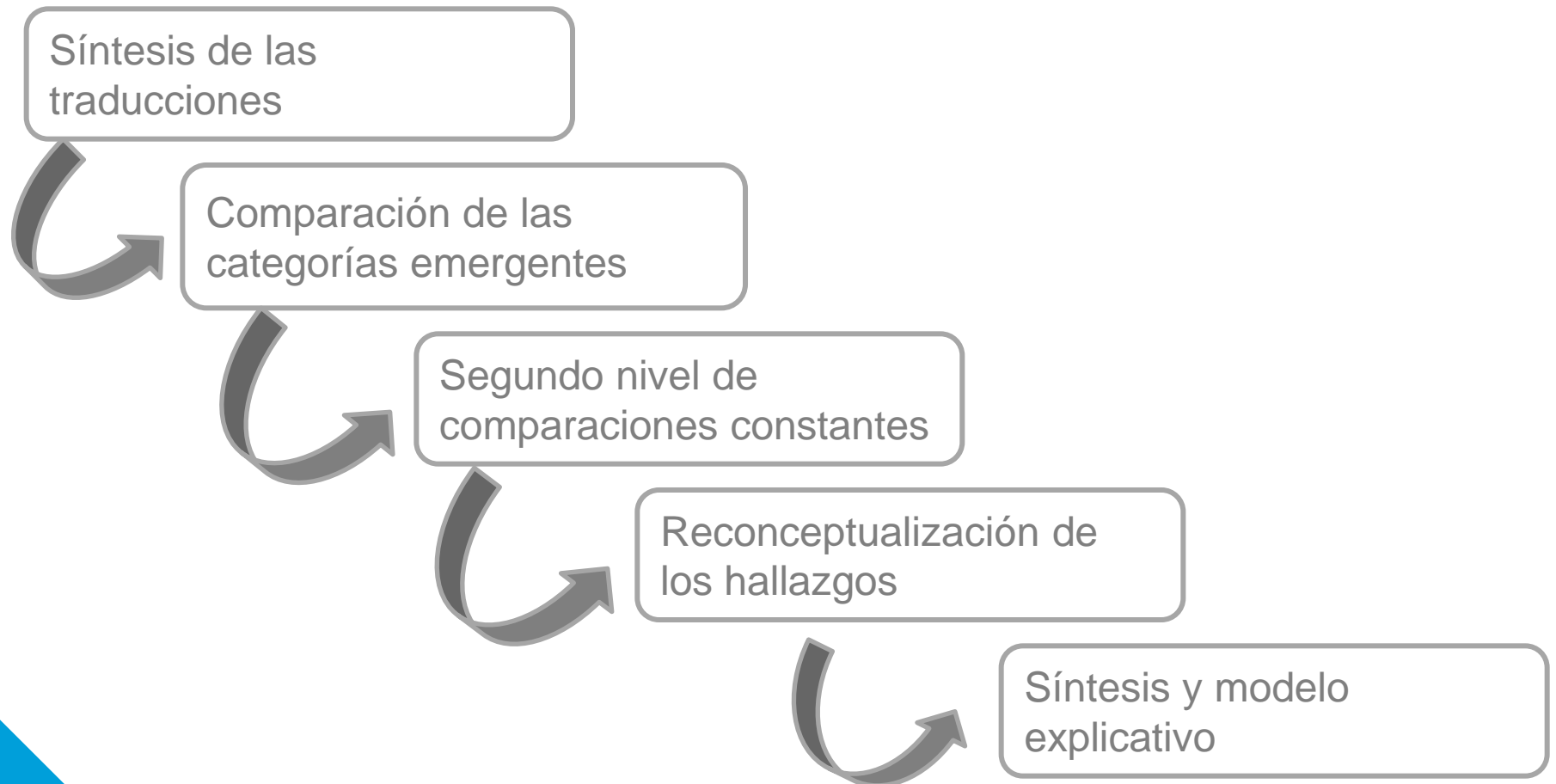
1. Lavery JV, Boyle J, Dickens BM, Maclean H, Singer PA. Origins of the desire for euthanasia and assisted suicide in people with HIV-1 or AIDS: a qualitative study. *Lancet*. 2001; 358:362-7.
2. Kelly B, Burnett P, Pelusi D, Badger S, Varghese F, et al. Terminally ill cancer patients' wish to hasten death. *Palliat Med*. 2002;16:339-45
3. Coyle N, Sculco L. Expressed desire for hastened death in seven patients living with advanced cancer: a phenomenologic inquiry. *Oncol Nurs Forum*. 2004; 31:699-709
4. Mak YY, Elwyn G. Voices of the terminally ill: uncovering the meaning of desire for euthanasia. *Palliat Med*. 2005; 19: 343-50
5. Pearlman RA, Hsu C, Starks H, Back AL, Gordon JR, et al. Motivations for physician-assisted suicide. *J Gen Intern Med*. 2005; 20: 234-9
6. Schroepfer TA. Mind frames towards dying and factors motivating their adoption by terminally ill elders. *J Gerontol*. 2006; 61: S129-139
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: 165-71

**Método de Síntesis:
Meta-etnografía de
Noblit & Hare¹⁵**



15. Noblit G, Hare R (1988) Meta-ethnography: Synthesizing qualitative studies Newbury Park: Sage.

Línea de argumentación

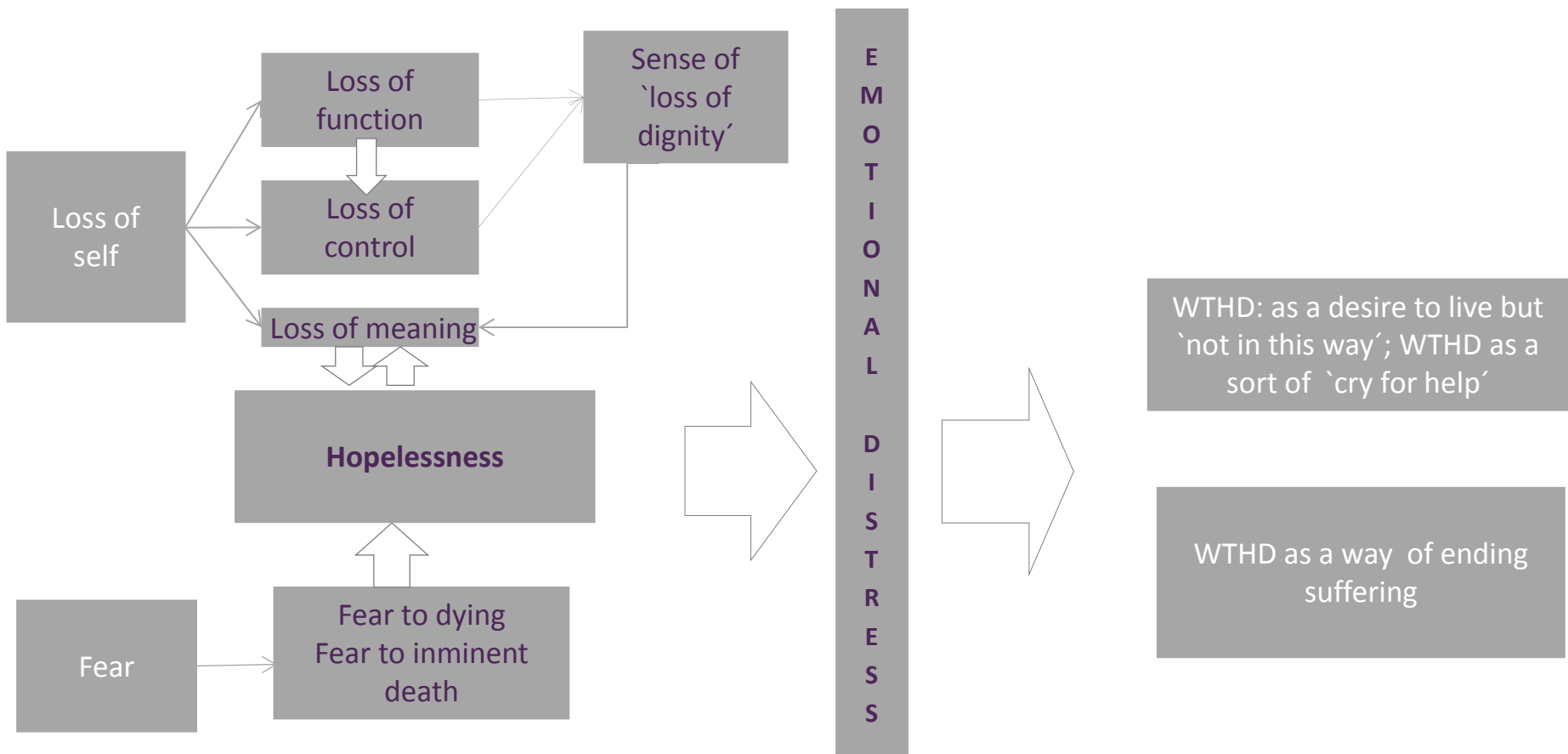


MODELO EXPLICATIVO: DAM en pacientes con enfermedad avanzada

Physical – Psychological - Spiritual suffering



Wish to hasten death in response to suffering



WTHD A KIND OF CONTROL,
'To have an ace up one's sleeve'

Síntesis de estudios cualitativos (meta-etnografía):

- A) WTHD es un **fenómeno reactivo** (respuesta a un sufrimiento multidimensional)
- B) WTHD tiene **diferentes significados** (no => genuino deseo de morir):
- Respuesta a sufrimiento físico/psicológico / espiritual/ existencial
 - Pérdida de sí mismo (incluye pérdida de sentido de la vida)
 - Miedo a morir
 - Un medio para acabar con el sufrimiento
 - Deseo de vivir, pero no de este modo
 - Una forma de control sobre la vida (“un por si a caso”)
- C) Estos significados, tienen una **relación causal** con el WTHD

Limitaciones

- La depresión no se exploró en todos los estudios incluidos en la revisión sistemática
- Estrategia de búsqueda
- Diferentes diseños de los estudios cualitativos primarios

What Lies behind the Wish to Hasten Death? A Systematic Review and Meta-Ethnography from the Perspective of Patients

Cristina Monforte-Royo^{1,6}, Christian Villavicencio-Chávez^{2,6}, Joaquin Tomás-Sábado³, Vinita Mahtani-Chugani^{4,5}, Albert Balaguer^{1,6*}

1 Medicine and Health Sciences School, Universitat Internacional de Catalunya, Barcelona, Spain, **2** Institut Català d'Oncologia, Barcelona, Spain, **3** Gimbernat School of Nursing, Universitat Autònoma de Barcelona, Barcelona, Spain, **4** Research Unit, Hospital Nuestra Señora de Candelaria and Primary Health Care, Tenerife, Spain, **5** National Network for Biomedical Research in Epidemiology and Public Health, Instituto de Salud Carlos III, CIBERESP, Barcelona, Spain, **6** Centre de Recerca i Estudis Biètics (CREB), Universitat Internacional de Catalunya, Barcelona, Spain

Abstract

Background: There is a need for an in-depth approach to the meaning of the wish to hasten death (WTHD). This study aims to understand the experience of patients with serious or incurable illness who express such a wish.

Methods and Findings: Systematic review and meta-ethnography of qualitative studies from the patient's perspective. Studies were identified through six databases (ISI, PubMed, PsycINFO, CINAHL, CUIDEN and the Cochrane Register of Controlled Trials), together with citation searches and consultation with experts. Finally, seven studies reporting the experiences of 155 patients were included. The seven-stage Noblit and Hare approach was applied, using reciprocal translation and line-of-argument synthesis. Six main themes emerged giving meaning to the WTHD: WTHD in response to physical/psychological/spiritual suffering, loss of self, fear of dying, the desire to live but not in this way, WTHD as a way of ending suffering, and WTHD as a kind of control over one's life ('having an ace up one's sleeve just in case'). An explanatory model was developed which showed the WTHD to be a reactive phenomenon: a response to multidimensional suffering, rather than only one aspect of the despair that may accompany this suffering. According to this model the factors that lead to the emergence of WTHD are total suffering, loss of self and fear, which together produce an overwhelming emotional distress that generates the WTHD as a way out, i.e. to cease living in this way and to put an end to suffering while maintaining some control over the situation.

Conclusions: The expression of the WTHD in these patients is a response to overwhelming emotional distress and has different meanings, which do not necessarily imply a genuine wish to hasten one's death. These meanings, which have a causal relationship to the phenomenon, should be taken into account when drawing up care plans.

Citation: Monforte-Royo C, Villavicencio-Chávez C, Tomás-Sábado J, Mahtani-Chugani V, 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

Editor: James Kilner, University College London, United Kingdom

Received: January 13, 2012; **Accepted:** April 13, 2012; **Published:** May 14, 2012

Copyright: © 2012 Monforte-Royo et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Funding: This work was supported by a grant (PR.5177/09) from Col·legi Oficial d'Infermers de Barcelona and a National Grant from Instituto de Salud Carlos III, Spain (PI11-01353). The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Competing Interests: The authors have declared that no competing interests exist.

* Email: abalaguer@usc.uic.es

Introduction

For several decades now, clinicians and researchers have shown a growing interest in analysing the wish to hasten death (WTHD) in the context of serious or incurable illness. This phenomenon seems to affect a considerable number of patients, especially those facing the end of life or advanced stages of their illness [1,2,3]. In this regard, medical advances that increase life expectancy and disease chronicity, as well as other social phenomena found in developed societies (e.g. family or community breakdown), may contribute to making the WTHD more common [4,5,6,7].

One of the difficulties faced by any clinical study of the WTHD is how to define the concept. Indeed, studies have not distinguished clearly between a general wish to die, the wish to hasten death and requests for euthanasia or physician-assisted

suicide [8]. Thus, one finds the indistinct use of terms such as 'wish to die' [9], 'want to die' [10] or 'desire to die' [11,12], as well as 'wish to hasten death' [13,14], 'desire for early death' [15] and other related expressions or synonyms for requests for euthanasia or assisted suicide, such as 'death-hastening request' [16], 'request to die' [17], 'request for euthanasia' [18] and 'request for physician-assisted suicide' [19].

In addition to this lack of consensus regarding the conceptual definition and terminology of the WTHD, another aspect to consider is that the phenomenon tends to vary over time, depending on the stage or circumstances in which patients find themselves [11,20,21,22], and this makes it enormously difficult to estimate its frequency. Nevertheless, some studies have sought to provide data regarding its epidemiology and prevalence in different settings [23,24,25]. Noteworthy in this regard has been

Y tras un tiempo...

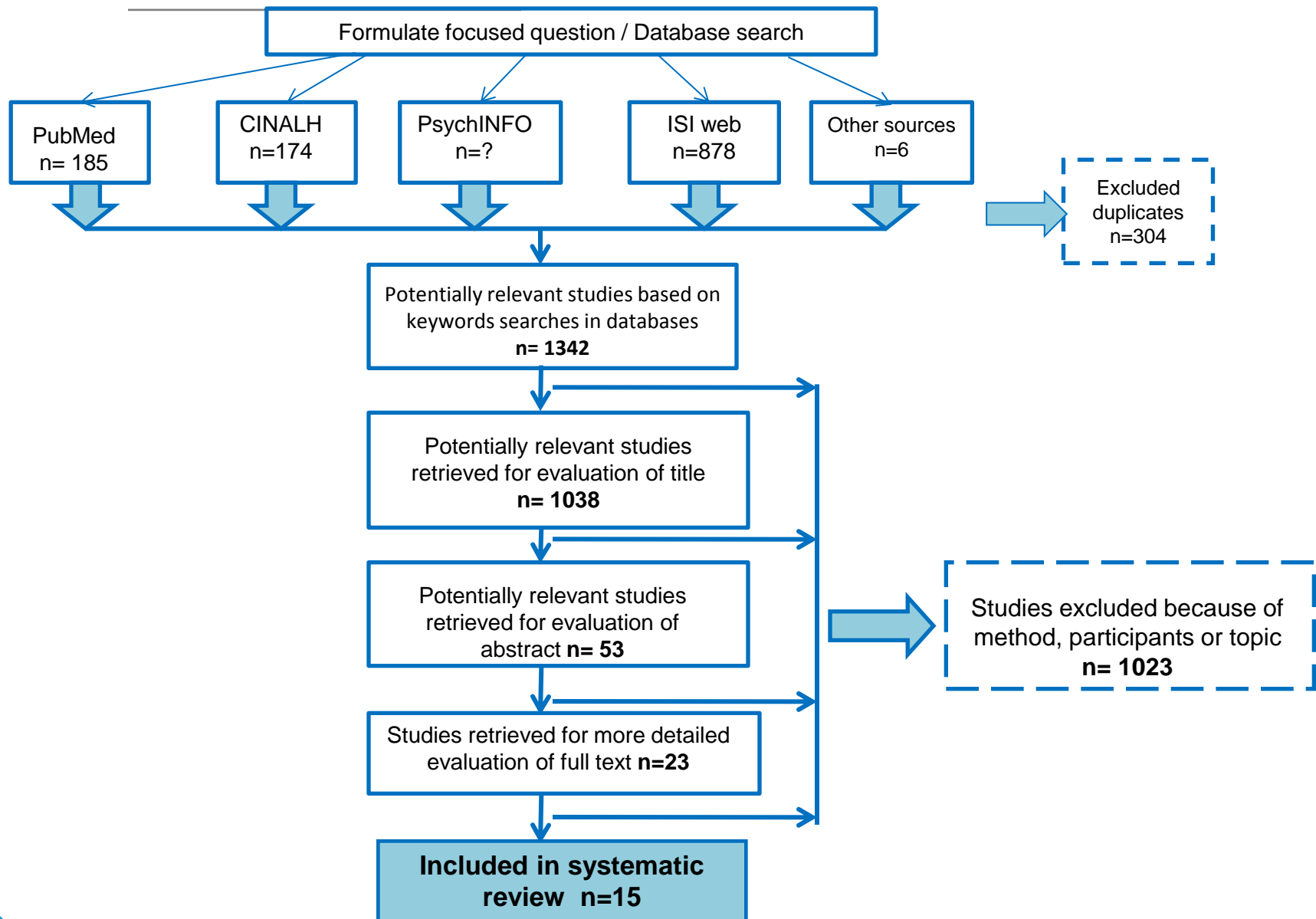
Necesidad de una actualización de la revisión sistemática

Método:

Estrategia de Búsqueda

	#	Bibliographic search strategy
WTHD Topic	1. Desire to hasten death/ 2. Wish to hasten death/ 3. Euthanasia/ 4. Assisted Suicide/ 5. Decisions end of life/ 6. Wish to die 7. #1 or #2 or #3 or #4 or #5 or #6	29. structured[TIAB] 30. guide[TIAB] 31. guides[TIAB] 32. #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31
Setting	8. Palliative care 9. End of life care 10. #8 or #9	33. interview*[TIAB] 34. discussion*[TIAB] 35. questionnaire*[TIAB] 36. #33 or #34 or #35 37. #32 AND #36
Population	11. Chronic disease/ 12. Chronic illness/ 13. Advanced disease/ 14. Advanced illness/ 15. Advanced cancer/ 16. Life limiting illness 17. Terminally ill 18. Life threatening illness 19. Life threatening condition 20. #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 21. #7 and #10 and #20	38. "focus group"[TIAB] 39. "focus groups"[TIAB] 40. qualitative[TIAB] 41. ethnograph*[TIAB] 42. fieldwork[TIAB] 43. "field work"[TIAB] 44. "key informant"[TIAB] 45. #37 or #38 or #39 or #40 or #41 or #42 or #43 46. #37 or #45
Filtro cualitativo	22. "semi-structured" [TIAB] 23. Semistructured [TIAB] 24. unstructured[TIAB] 25. informal[TIAB] 26. "in-depth"[TIAB] 27. indepth[TIAB] 28. "face-to-face"[TIAB]	47. "interviews as topic"[Mesh] 48. "focus groups"[Mesh] 49. narration[Mesh] 50. qualitative research[Mesh] 51. "personal narratives as topic"[Mesh] 52. #47 or #48 or #49 or #50 or #51 53. #46 or #52
Key to abbreviations as used in Medline (PubMed): *, truncation; tw, text word; adj, adjective		

Método: Selección de estudios



Qualitative Studies Included (n=8)

Quality Assessment: CASP

- Nilmanat (2010) → Tailandia
- Stiel (2010) → Alemania
- Dees (2011) → Holanda
- Broom (2012) → Australia
- Ohnsorge (2012) → Suiza
- Ohnsorge (2014) → Suiza
- Ohnsorge (2014) → Suiza
- Pestinger (2015) → Alemania

Análisis preliminar

Categories/Subcategories	Study Reference							
	Nilmanat	Stiel	Dees	Broom	Ohnsorge	Ohnsorge	Ohnsorge	Pestinger
1. Wish to hasten death in response to physical-psychological-spiritual Suffering	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2. Loss of Self:								
Loss of function	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Loss of control	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sense of 'loss of dignity'	Yes	Yes	Yes	Yes	Yes	Yes	Yes	--
Loss of meaning	--	Yes	Yes	--	Yes	Yes	Yes	Yes
3. Fear:								
Fear to dying process	--	Yes	Yes	--	Yes	Yes	Yes	Yes
Fear to imminent death	--	Yes	Yes	Yes	--	--	--	Yes
4. WTHD: as a desire to live but 'not in this way'; as a sort of 'cry for help'	--	Yes	Yes	Yes	Yes	Yes	Yes	Yes
5. WTHD: as a way of ending suffering	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
6. WTHD: a kind of control of my life 'to have an ace up one's sleeve'	--	Yes	Yes	--	Yes	Yes	Yes	Yes

**Gracias por
vuestra atención**