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Patients' experiences of unbearable suffering in assisted dying requests in Spain and Switzerland: A qualitative study of common patterns of expressions

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ABSTRACT

In most countries where assisted dying is regulated, unbearable suffering is a key eligibility criterion. Yet, due to its deeply subjective nature, the assessment of suffering by third parties remains a challenge. Few studies have examined how patients themselves describe this experience. This cross-national qualitative study explores how individuals requesting assisted dying express and describe their experiences of unbearable suffering in Spain and Switzerland. Two parallel projects conducted between 2022 and 2025 used in-depth, semi-structured interviews with people seeking assisted dying. Combined datasets from 46 participants were analyzed using secondary data analysis, to identify common patterns of expressions using metatheme analysis. Five patterns of expression of unbearable suffering emerged. Listening to patients' own accounts offers a clearer understanding of the complexity of unbearable suffering. These findings may support more nuanced assessments, guide healthcare professionals and families, and inform public debate on assisted dying.

Introduction

Unbearable suffering constitutes, along with decision-making capacity, a central eligibility criterion for individuals requesting access to assisted dying (AD), an umbrella term for practices of euthanasia and assisted suicide (Radbruch et al., 2016), in most countries where the practice is legal. Among the 32 jurisdictions that have regularized access to assisted dying, 18 explicitly defined this requirement in their legislation and in one case, this requirement was not included in the law, but appeared in formal guidelines (Table 1).

While existing literature points to a lack of consensual definitions of what constitutes unbearable suffering in the context of assisted dying (Dees et al., 2010; Ortega-Galán et al., 2022), most authors follow Eric J. Cassell's (2018) account of suffering, according to which it is a subjective and multidimensional experience defined "as the state of severe distress associated with events that threaten the intactness of the person" (Cassell, 1998). Hence, some authors have described unbearable suffering in the context of assisted dying as a personal and subjective experience of an actual or perceived impending threat to the integrity or life of the person with a significant duration and fluctuation in intensity, which overwhelms one's bearing capacity (Dees et al., 2011; Ruijs et al., 2009). However, accounts of unbearable suffering given by persons who request assisted dying themselves are fairly uncommon (Parra Jounou et al., 2025; Xu et al., 2024), and the nature of this lived

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Table 1. Mention of suffering as an eligibility criterion to access assisted dying by jurisdiction.

Jurisdiction/year	Legislative resource		Eligibility criteria of unbearable/intolerable suffering
Australia (Queensland) 2021	https://www.legislation.qld.gov.au/view/pdf/asmade/act-2021-017	YES	Part 2. 10. Criteria: "is causing suffering that the person considers to be **intolerable**"
Australia (Australia Capital Territory) 2024	https://www.legislation.qld.gov.au/view/pdf/asmade/act-2021-017	YES	Part 2. 11. Criteria: "they are **suffering intolerably** in relation to the relevant conditions"
Australia (South Australia) 2021	https://www.legislation.sa.gov.au/_legislation-documents/lz/c/a/voluntary-assisted-dying-act-2021/current/2021.29.auth.pdf	YES	Part 3. 26. Criteria: "the person must be diagnosed with a disease, illness or medical condition that (d): is causing **suffering** to the person that cannot be relieved in a manner that the person considers **tolerable**"
Australia (South Wales) 2022	https://www.legislation.sa.gov.au/_legislation-documents/lz/c/a/voluntary-assisted-dying-act-2021/current/2021.29.auth.pdf	YES	Part 2. 16. Criteria: " the person is diagnosed with at least 1 disease, illness or medical condition that—(iii) is causing **suffering** to the person that cannot be relieved in a way the person considers tolerable."
Australia (Tasmania) 2021	https://www.legislation.sa.gov.au/_legislation-documents/lz/c/a/voluntary-assisted-dying-act-2021/current/2021.29.auth.pdf	YES	Part 3. 14. Criteria: "When person is **suffering intolerably** in relation to relevant medical condition" And specifies: (b) **persistent suffering** that is, in the opinion of the person, intolerable is being caused to the person by any one or more of the following: i. the relevant medical condition or the relevant medical condition together with the person's other medical conditions; ii. **anticipation of the suffering**, or expectation, based on medical advice, of the suffering, that may arise from the relevant medical condition or from the relevant medical condition together with the person's other medical conditions; iii. the treatment that the person has received or the combination of that treatment with the treatment of other medical conditions of the person; iv. anticipation of the suffering, or expectation, based on medical advice, of the suffering, that may arise from the treatment that the person may receive in relation to the relevant medical condition or the combination of that treatment with the treatment of the person's other medical conditions; v. the complications of a medical kind arising from, or related to, the treatment of the relevant medical condition or the combination of that treatment with the treatment of the person's other medical conditions; vi. anticipation of the suffering, or expectation, based on medical advice, of the suffering, that may arise from the complications of a medical kind arising from, or related to, the treatment of the relevant medical condition or the combination of that treatment with the treatment of the person's other medical conditions;
Australia (Victoria) 2017	https://content.legislation.vic.gov.au/sites/default/files/8caaf3b4-28f6-3ad1-acf3-e3c46177594e_17-61aa003%20authorised.pdf	YES	Part 2. 9. Criteria: "the person must be diagnosed with a disease, illness or medical condition that—(iv) is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable."

(*Continued*)

Table 1. Continued.

Jurisdiction/year	Legislative resource		Eligibility criteria of unbearable/intolerable suffering
Australia (Western) 2019	https://www.legislation.wa.gov.au/legislation/prod/filestore.nsf/FileURL/mrdoc_42491.pdf/$FILE/Voluntary%20Assisted%20Dying%20Act%20 2019%20-%20%5B00-00-00%5D.pdf	YES	Part 2. 16. Criteria: "the person is diagnosed with at least 1 disease, illness or medical condition that—is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable."
Austria 2021	https://wfrtds.org/wp-content/uploads/2022/01/Sterbeverfugungsgesetz-in-Bundesgesetzblatt.pdf	YES	Art. 1.2 § 6 (3), 2. "is suffering from a serious, permanent illness (Section 120(1) ASVG) with persistent symptoms, the consequences of which permanently impair the person concerned in their overall lifestyle; whereby the illness causes a **state of suffering that cannot be averted in any other way** for the person concerned"
Belgium 2003	https://www.ejustice.just.fgov.be/cgi_loi/article.pl?language=fr&lg_txt=f&type=&sort=&numac_search=&cn_search=2002052837&caller=SUM&&view_numac=2002052837f#LNK0002	YES	Chapter 2. Art.3. Criteria: "the patient [of legal age or emancipated minor] is in an irremediable medical situation and experiences **constant and unbearable physical or psychological suffering that cannot be alleviated** and that results from a serious and incurable accidental or pathological condition"
Canada 2016	https://www.ejustice.just.fgov.be/cgi_loi/article.pl?language=fr&lg_txt=f&type=&sort=&numac_search=&cn_search=2002052837&caller=SUM&&view_numac=2002052837f#LNK0002	YES	Part 1. IV. Criteria: "experiencing **enduring physical or psychological suffering**, due to the illness, disease, disability or state of decline, that is **intolerable** to the person and **cannot be relieved** in a manner that they consider acceptable"
Colombia 1997	https://www.corteconstitucional.gov.co/relatoria/2021/C-233-21.htm	YES	Previou sentence C-239/1997.3. Criteria: "terminal patients that experience **intense suffering**." Sentence C-233/21,W. E443 also adds serious and incurable diseases. Section V.427: "Every person has access and a privileged epistemic authority regarding *their* suffering. The others, even a healthcare professional, cannot have a direct knowledge of a patient's suffering." Section 428: "Denying or questioning its existence or significance does not only mean overshadowing or degrading the patient's experience; it also constitutes, due to the impossibility to have a direct knowledge of it, an abuse toward the person's autonomy and dignity. Hence, the imposition of an external criteria to evaluate its significance, questioning about its visibility, or the demand of certainty in its existence go far beyond its comprehension as another person's subjective experience." Section V. 432, "In case of disagreement between patients and physicians on the existence of suffering, the subjective dimension should prevail. Section V. 438: "in the exercise of the fundamental right to die with dignity, there is a subrule that privileges the subjective dimension [of suffering] ."
Ecuador 2024	https://esacc.corteconstitucional.gob.ec/storage/api/v1/10_DWL_FL/e2NhcnBldGE6J3RyYW1pdGUnLCB1dWlkOidlNzVjZThhMS1iMGM0LTQ0OWMtYmEyMy01MTdlYzVkYTY3NGQucGRmJ30=	YES	10.1. Criteria: "suffering an **intense suffering** resulting from a physical serious and irreversible condition or a serious and incurable disease."
Italy (Tuscany) 2025	https://esacc.corteconstitucional.gob.ec/storage/api/v1/10_DWL_FL/e2NhcnBldGE6J3RyYW1pdGUnLCB1dWlkOidlNzVjZThhMS1iMGM0LTQ0OWMtYmEyMy01MTdlYzVkYTY3NGQucGRmJ30= https://www.cortecostituzionale.it/scheda-pronuncia/2019/242	YES	Art. 2.1. Refers to the criteria described in the Sentence 242/2019 of the Italian Constitutional Court. Sentence 242/2019: *considerato un diritto* 2.3.: Criteria"(b) Source of physical or psychological suffering, that the person finds completely intolerable."

(*Continued*)

Table 1. Continued.

Jurisdiction/year	Legislative resource		Eligibility criteria of unbearable/intolerable suffering
Luxembourg 2009	https://legilux.public.lu/eli/etat/leg/loi/2009/03/16/n2/jo	YES	Chapter 2. Art. 2, 3). Criteria: "the is in an irremediable medical condition and experiences **constant and unbearable physical or psychological suffering, without prospect of improvement,** that results from a serious and incurable accidental or pathological condition"
New Zealand 2019	https://www.legislation.govt.nz/act/public/2019/67/en/latest/#DLM7285950	YES	Part 1.5 (1)(e). Criteria: "experiences **unbearable suffering** that cannot be relieved in a manner that the person considers tolerable"
Portugal 2023 - Not Implemented.	https://diariodarepublica.pt/dr/detalhe/lei/22-2023-213498831	YES	Chapter 1. Art. 3. Criteria: "in a situation of **highly intense suffering**."
Spain 2021	https://diariodarepublica.pt/dr/detalhe/lei/22-2023-213498831	YES	Chapter 2. Art.5. Criteria: "Suffering from a serious and incurable illness or a serious, chronic, and incapacitating condition." These conditions are defined in Chapter 1. Art. 3c and 3b, respectively. Chapter 1. Art. 3c. Serious and incurable illness: "that which by its nature causes constant and unbearable physical or psychological suffering with no possibility of relief that the person considers tolerable, with a limited life prognosis, in a context of progressive fragility." Chapter 1. Art. 3b. Serious, chronic, and incapacitating condition: "a situation that refers to limitations that directly affect physical autonomy and daily living activities, so that it does not allow self-sufficiency, as well as the ability to express oneself and relate, and that are associated with constant and intolerable physical or psychological suffering for the sufferer, with the certainty or high probability that such limitations will persist over time without the possibility of cure or appreciable improvement. Sometimes it may imply absolute dependence on technological support."
Switzerland 1942	https://www.fedlex.admin.ch/eli/cc/54/757_781_799/fr#art_115 https://www.fedlex.admin.ch/eli/cc/54/757_781_799/fr#art_115	NO*	Not a criteria in the Article 115 of the Penal Code. But it is cited in the federal medical-ethical guidelines. SAWMS guideline: "Severe suffering: The severity of the patient's symptoms and/or functional impairments is to be substantiated by an appropriate diagnosis and prognosis. For the patient, they are a source of intolerable suffering (cf. Section 2.4). The patient's desire not to continue living in this situation of intolerable suffering is comprehensible for the physician on the basis of the previous history and repeated discussions. Since intolerable suffering is not objectively determinable, the physician cannot be required to make such a determination. The physician must, however, document that he or she has taken adequate care to gain an appreciation of the patient's concrete, individual situation, such as to render its intolerability comprehensible"
The Netherlands 2002	https://wetten.overheid.nl/BWBR0012410/2021-10-01	YES	Chapter 1, Art. 2, b. Criteria: "the physician] has become convinced that the patient was **suffering unbearably** and without prospect of improvement"
United Kingdom (Isle of Man) 2023 - Implem. 2027	https://legislation.gov.im/cms/images/LEGISLATION/BILLS/2023/2023-0005/2023-0005.pdf	No	N/A

(*Continued*)

Table 1. Continued.

Jurisdiction/year	Legislative resource		Eligibility criteria of unbearable/intolerable suffering
Uruguay 2025	https://www.impo.com.uy/diariooficial/2025/11/05/documentos.pdf	YES	Art. 2. Criteria: "as a consequence of incurable and irreversible illnesses or conditions, the person suffers from **unbearable suffering**, in all cases with serious and progressive decay in their quality of life."
USA (California) 2016	https://www.impo.com.uy/diariooficial/2025/11/05/documentos.pdf	NO	N/A
USA (Colorado) 2016	https://www.sos.state.co.us/pubs/elections/Initiatives/titleBoard/filings/2015-2016/145Final.pdf	NO	.N/A
USA (Delaware) 2025	https://www.sos.state.co.us/pubs/elections/Initiatives/titleBoard/filings/2015-2016/145Final.pdf	NO	N/A
USA (District of Columbia) 2016	https://dchealth.dc.gov/sites/default/files/dc/sites/doh/page_content/attachments/Death%20With%20Dignity%20Act.FINAL_.pdf	NO	N/A
USA (Hawaii) 2019	https://kokuamau.org/wp-content/uploads/OCOC-Act2.pdf	NO	N/A
USA (Illinois) 2025 - Impl. 2026	https://www.ilga.gov/Legislation/ILCS/Articles?ActID=4646&ChapterID=35&Chapter=PUBLIC%20HEALTH&MajorTopic=HEALTH%20AND%20SAFETY&Print=True	NO	N/A
USA (Maine) 2019	https://kokuamau.org/wp-content/uploads/OCOC-Act2.pdf	NO	N/A
USA (New Jersey) 2019	https://www.njconsumeraffairs.gov/Statutes/Medical-Aid-in-Dying-for-the-Terminally-Ill-Act.pdf	NO	N/A
USA (New Mexico) 2021	https://endoflifeoptionsnm.org/wp-content/uploads/2021/07/CH132-HB47-2021.pdf	NO	N/A
USA (Oregon) 1998	Oregon Death with Dignity Act	NO	N/A
USA (Vermont) 2013	https://www.patientchoices.org/text-of-act-39.html	NO	N/A
USA (Washington) 2009	https://app.leg.wa.gov/rcw/default.aspx?cite=70.245&full=true#70.245.040	NO	N/A

experience and what makes such suffering *unbearable* seems still elusive to research.

From this standpoint, the study aims to explore individuals' experiences and expressions of unbearable suffering in the context of requests for assisted dying across two European countries where this practice is permitted. In Spain, assisted dying is predominantly performed through physician-administered euthanasia, although self-administered assisted dying is also legally possible. The law requires that the person "suffers from a serious and incurable disease or a serious, chronic, and incapacitating condition under the terms established in this Law" to access the practice (Oficial del Estado, 2021). Although suffering is not explicitly mentioned in that particular article, the definitions of what is considered a serious and incurable disease or a serious, chronic, and incapacitating condition include the existence of "constant and unbearable physical or psychological suffering" (Oficial del Estado, 2021). The assessment of what is known as "the euthanasic context" must be conducted by three external parties: the referring physician, the consulting physician, and the Guarantee and Evaluation Commission. In Switzerland, the federal law prohibits euthanasia but permits assisted suicide under Article 115 of the Swiss Penal Code. Unlike Spain, the law does not specifically mention any eligibility criteria, nor specify that it should be delivered or coordinated necessarily by medical practice. However, since 2018, the Swiss Academy of Medical Sciences has issued medical-ethical guidelines to support healthcare professionals in assessing individuals' eligibility for assisted suicide (Académie Suisse des Sciences Médicales, 2021). These guidelines specify that one criterion that give access to assisted suicide is the experience of unbearable suffering. It is referred to both as "extreme suffering" and "unbearable suffering" and is defined as suffering that is subjectively assessed and experienced by the patient, persistent, progressive, and with no hope of relief. In addition, they serve as an informal basis for right-to-die associations, which are the main actors in supporting individuals to obtain the prescription for the lethal drug, and healthcare professionals to assess the eligibility of individuals requesting assisted suicide.

Exploring patients' experiences of unbearable suffering in the context of requests for assisted dying, the present study addresses the following question: how is unbearable suffering expressed across national contexts among patients requesting assisted dying in Spain and Switzerland? Adopting a patient-centered perspective by investigating the phenomenon directly through patients' own accounts, the study aims to

identify common patterns of expression in the ways unbearable suffering is articulated by patients requesting assisted dying. It also has implications for how unbearable suffering is understood in legal and clinical contexts, including the relationship between patients' accounts and existing eligibility frameworks.

Methodology

Study design

This qualitative study is a collaboration between two independent research projects conducted in Spain and Switzerland, exploring cross-national expressions and experiences of unbearable suffering among individuals pursuing assisted dying:

- **Spanish project:** The study *End-of-life narratives of patients requesting MAID* was launched to investigate the experiences, values, and emotions of patients actively engaging in an assisted dying request across Spain (Vallès-Poch et al., 2023). The project, conducted from 2022 to 2024, aimed to explore the circumstances of and motivations for this choice; to identify the contexts in which assisted dying was requested; and to understand the impact of a positive or negative resolution and potential difficulties along the process.
- **Swiss project:** This study is part of a Swiss national exploratory research project *Understanding altruism at the end-of-life: an interdisciplinary approach,* conducted between October 2023 and July 2025 (Bernard et al., 2024). This project investigates patients' manifestations of altruism at the end of life in different contexts. The present study draws on the subproject exploring motivations underlying individuals' decision to pursue an assisted suicide across Switzerland, with specific attention to altruistic motivations.

This collaboration emerged after each project's primary data analysis. Although the exploration of patients' expressions of unbearable suffering was not the initial focus, both studies identified it as a salient and central element in participants' accounts of requesting assisted dying. Discussions between the research teams further suggested that patients in both countries might share similar patterns of expressing this suffering.

The collaboration brought together two original datasets to investigate empirically a common phenomenon and identify shared patterns of expressions in patients' experiences. While cross-national qualitative collaborations are often considered valuable, detailed methodological guidance remains limited and existing studies typically rely on jointly designed research processes, from data collection to analysis, to compare manifestations of a phenomenon across socio-cultural contexts (Hantrais & Mangen, 1996; Heath et al., 2024; Maclean et al., 2023; Wild et al., 2023).

In contrast, this study draws on two independently collected datasets and aims to identify and describe common expressions without aiming to produce a systematic comparison between countries. We therefore designed our study as a secondary analysis of both datasets, guided by a shared research question, and developed findings based on the common expressions identified. This approach enabled the identification of cross-national patterns in how patients experience and express unbearable suffering.

Setting and participants

Target populations were defined and recruitment procedures were conducted independently, but followed similar approaches in both studies: each targeted individuals in Switzerland and Spain who were requesting assisted dying, using purposive and snowball sampling. This approach provided flexibility and supported diversity in end-of-life experiences, which is essential given the challenges of accessing this population due to health vulnerability and unstable circumstances affecting recruitment.

Both studies applied identical inclusion criteria: participants had to (a) be in the process of requesting assisted dying, regardless of the outcome; (b) be adults; and (c) be able to communicate. Focusing rather on the willingness of patients to request assisted dying than the status of their request, the study includes not only people with a granted request, but also people under evaluation and people with a negative resolution.

Recruitment was carried out in collaboration with healthcare professionals and right-to-die associations. These partners identified potential participants, shared study information (e.g., flyers, websites), and obtained consent for researchers to make contact. Researchers then approached interested individuals, provided oral and written information about the study's aims, procedures, and confidentiality, and obtained written informed consent prior to participation. In both studies, recruitment continued until researchers estimated having gathered sufficiently rich and diverse data.

Data collection

Data collection was conducted independently but followed similar procedures in each country. In Switzerland, it took place from October 2023 to July 2025; in Spain, from November 2022 to November 2024.

In both studies, in-depth interviews were used to explore participants' descriptions of their condition and lived experience. Open-ended, inductive questions enabled participants to define in their own terms what constituted unbearable suffering, while elaborating and reflecting freely on their experiences. Although each project developed its own semi-structured interview guide, both included similar guiding questions, such as: What kind of suffering would you say has led you to request assisted dying? How would you describe it? Since when would you say you experience this situation? Given the sensitive and potentially distressing nature of the topic, special attention was paid to participants' emotional well-being throughout the study, and participants were reminded that they could pause or stop the interview at any time without providing justification.

Interviews were conducted in participants' native languages - Spanish and Catalan for Spain, and French, Italian and German for Switzerland - and took place in either hospital rooms or participants' homes. In Spain, they were conducted by IPJ (a PhD student in philosophy, and a nurse), MVML (a PhD student in philosophy, and a nurse), MVP (a PhD student in bioethics), ROL (an assistant professor in bioethics and communication), and DRA (a full professor in empirical bioethics). In Switzerland, the interviews were conducted by SB (a PhD student in medical humanities) under the supervision of CG (a full professor and palliative care physician and leader of the Swiss project). Researchers were trained to identify and respond appropriately to signs of emotional distress during the interviews. To support researchers' emotional well-being, opportunities were provided to discuss challenges through structured supervision, team meetings within each project, post-interview phone availability, and access to external psychological support was also offered when needed (Martínez-López et al., 2026). Researchers were also invited to make field notes during all data collection and analysis to support the interpretation of data and document their thoughts and interpretation about their respective studies.

Interviews lasted between 15 minutes to 3 hours. They were audio-recorded, transcribed verbatim in their original languages either manually or with AI assistance using Aiko (Sindre, 2024), and manually corrected for accuracy and anonymization (i.e., mainly names and locations). All transcripts were anonymized by removing identifying details and were securely stored in each institution's restricted-access cloud environment. To restrict data access, only selected anonymized quotations were shared with the parallel researchers' team during the secondary data analysis phase. Selected quotations were translated either manually or with the help of DeepL into English, and translations were revised by the interviewer and double-checked with a native speaker.

Both studies complied with national and institutional ethical requirements. Ethical approval was obtained from Biothical Committee of Andalusia in Spain (1422-N-22), and from the Ethics Committee of the Canton of Vaud, Zürich and Ticino in Switzerland (number 2023-00088, on the 23rd of June 2023). The study followed the ethical principles of the 2024 revised version of the Declaration of Helsinki. This study adhered to COREQ reporting standards for qualitative research.

Data analysis

Using Wutich et al. (2021) metatheme analysis, a secondary data analysis was conducted on the original datasets from each country (Wutich et al., 2021). This approach enables researchers to "identify overarching metathemes and inter-relationships between themes across primary qualitative datasets" (Wutich et al., 2021) in different settings and countries by addressing a shared research question, supporting the development of rich, descriptive accounts of common patterns of unbearable suffering.

This multi-step analysis required both national teams to return to the original data using a deductive approach focusing on identifying empirical expressions and descriptions of unbearable suffering. Metathemes were developed iteratively through multiple rounds of refinement. First, SB and IPJ independently extracted relevant codes and themes from their initial thematic analyses (conducted with Braun and Clarke (2022) thematic analysis (Braun & Clarke, 2022)), compiled them in a separate document, and shared them with the research consortium. A series of collaborative meetings then enabled researchers to align the analytical focus, compare codes, and build an initial shared framework in which they compiled potential relevant codes and themes. During these discussions, teams clarified code meanings, assessed their relevance to the research question, identified commonalities across datasets, and examined divergences. Particular attention was paid to preserving semantic equivalence across languages and contexts during code comparison, including iterative validation of translated excerpts and reflexive discussions within the research team. Given the substantial overlap, the analysis prioritized shared patterns. This process ensured consistency while preserving contextual nuances.

In a second phase, the consortium conducted an in-depth, constant comparison of codes and themes, grouping logically similar codes into potential metathemes and integrating them into a shared coding tree (**Appendix 1**). Further meetings supported the refinement and consolidation of metathemes, grouping codes together into a coherent pattern. Metathemes were developed by grouping diverse but conceptually related excerpts into coherent and interpretable patterns across the two datasets. Findings are presented as analytical narratives supported by illustrative excerpts translated into English.

Results

Overview

A total of 46 semi-structured interviews were analyzed (Table 2). Participants ranged in age from 30 to 97, and the majority were women. Most participants had cancer, with a smaller number presenting neurological and chronic conditions. 20 participants had their requests for assisted dying granted at the moment of interview. Remaining participants were either under evaluation, waiting on their request to be granted, had already received a rejection, or weren't sure about

Table 2. Characteristics of participants.

Participant ID	Gender	Age	Underlying diseases	Status of request during interview	Follow-up of the request
SPAIN					
E1	Woman	57	Gastrointestinal cancer	Granted	Granted
E2	Woman	30	Borderline personality disorder	Rejected	Rejected
E3	Man	47	Polymorbidity + treatment-resistant chronic depression	Under evaluation	Rejected
E4	Man	68	Parkinson	Under evaluation	Granted
E5	Woman	41	Neuropathic pain + cystectomy, urostomy, colostomy, nephrostomy	Rejected	Rejected
E6	Woman	53	Tetraplegia + Recurent strokes + aphasia	Granted	Granted
E7	Man	56	Multiple sclerosis	Under evaluation	Granted
E8	Woman	51	Multiple sclerosis	Under evaluation	Unknown
E9	Woman	79	Epilepsy + Sjögren syndrome	Under evaluation	Granted
E10	Woman	55	Polymorbidity	Granted	Granted
E11	Woman	71	Degenerative joint disease	Granted	Granted
E12	Man	76	Trigeminal neuralgia	Granted	Granted
E13	Woman	52	Amyotrophic lateral sclerosis	Granted	Granted
E14	Man	96	Lung cancer	Granted	Died from natural death
E15	Man	69	Pancreatic cancer	Under evaluation	Unknown
SWITZERLAND					
PERS1102	Female	73	Renal failure	Granted	Granted
PERS1103	Female	65	SLA	Granted	Granted
PERO100	Female	66	Breast cancer	Under evaluation	Unknown
PEREF107	Male	83	Polymorbidity	Under evaluation	Unknown
PEREF105	Female	97	Polymorbidity	Granted	Granted
PERO106	Male	80	Throat cancer	Under evaluation	Unknown
PERS3101	Male	85	Bladder cancer	Under evaluation	Unknown
PERS3102	Male	83	ORL cancer	Granted	Granted
PERO104	Male	54	Lung cancer	Under evaluation	Unknown
PERO105	Male	74	Lung cancer	Under evaluation	Unknown
PERS1111	Male	69	Esophageal cancer	Granted	Granted
PERS1112	Male	50	Lung cancer	Under evaluation	Unknown
PERS1113	Female	88	Pancreatic cancer	Granted	Granted
PERS1118	Female	64	Acute pancreatitis	Granted	Granted
PERSO100	Female	82	Unknown cancer	Granted	Granted
PERS1121	Female	84	Bone cancer	Granted	Granted
PERS1122	Female	83	Unknown cancer	Rejected	Rejected
PERO107	Male	52	Colon cancer	Under evaluation	Unknown
PERO108	Female	35	Psychiatric disease	Under evaluation	Unknown
PERS1125	Male	90	Bilar cancer	Granted	Granted
PERS1127	Male	86	Renal failure	Granted	Granted
PERS1130	Female	93	Heart failure	Granted	Granted
PERS1131	Female	74	Breast cancer	Granted	Granted
PERS1132	Male	74	COPD	Under evaluation	Unknown
PERS1115	Male	59	Pancreatic cancer	Under evaluation	Unknown
PERS1141	Female	75	COPD	Under evaluation	Unknown
PERO109	Female	64	COPD	Under evaluation	Died from natural death
PATO110	Female	77	COPD	Under evaluation	Unknown
PERO111	Female	82	Colon cancer	Under evaluation	Unknown
PERS5112	Female	63	Heart failure	Under evaluation	Died from natural death
PERS1102	Female	73	Renal failure	Under evaluation	Unknown

continuing the request process. Including participants at different stages of the request process allowed us to capture the expression of suffering independent of the procedural outcome.

Shared patterns of unbearable suffering were grouped into five metathemes. Each theme illustrates one shared pattern identified in participants' accounts as one expression of unbearable suffering. Metathemes were developed to capture common expressions across participants' accounts rather than differences by personal characteristics, trajectories, or cultural background.

When describing their experiences, participants drew on one or multiple expressions; metathemes could accumulate or intertwine, each contributing distinctly to the overall experience. When multiple expressions were present, participants attributed varying degrees of intensity or significance to each. Regardless of whether one or several metathemes were involved, suffering was considered unbearable when the metatheme(s) in question were subjectively experienced as such.

Figure 1 **(a)** illustrates the five expressions participants used when explaining their experience of unbearable suffering. To illustrate how participants may refer to one or several metathemes and attribute varying levels of personal significance (i.e., intensity) to each, **(b)** and **(c)** present two fictive examples.

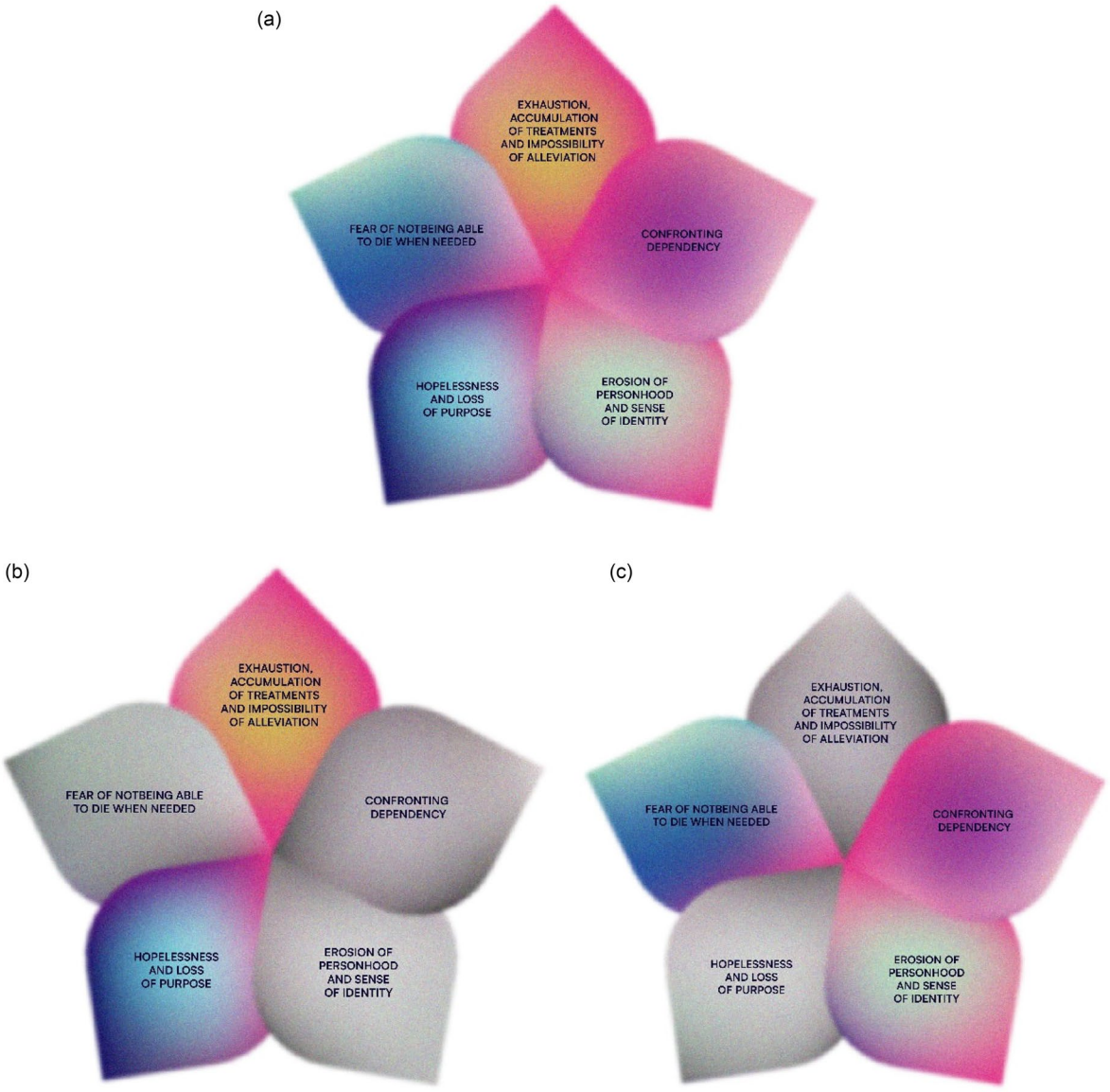


Figure 1. (a) Five metathemes identified as expressions of unbearable suffering. Figure 1 (b,c) Two examples of variations in metathemes (number of dimensions and significance) across participants' accounts..

Petal color indicates the degree of contribution to the experience of unbearable suffering: colored petals represent dimensions that contributed strongly, whereas grey petals represent those that did not.

Exhaustion, accumulation of treatments, and impossibility of alleviation

This metatheme illustrates how unbearable suffering is expressed as a profound exhaustion in participants' accounts. Participants specified that the particularity of this exhaustion is that it lasts over time and is closely related to their health deterioration, resulting from repeated attempts to find effective alternatives or treatments. Following diagnosis, participants described entering a prolonged, exhausting, and painful health trajectory characterized by the accumulation of medical episodes (such as repeated treatments and hospitalizations) alongside ineffective pain management.

The cumulative burden of unsuccessful treatments, repeated hospitalizations, and traumatic situations had a significant effect on the experience of unbearable suffering, as it was worsening its perceived intensity:

> *When there was the fecalum, second fecalum, I started to seriously think. I told myself that I had to find a solution since I'm all alone. That I could still make the decision on my own, that I still had the capacity for discernment. And now it's been reaffirmed again, because now it's the 3rd time. I'm sick and tired of it.* (PER1132, Switzerland)

> *I had the infection and from there I went maybe minimum 60 times in the operating room, and now I counted them up to 37 and after that I don't count them anymore.* (PERO104, Switzerland)

As a result, unbearable suffering emerged in their discourses through their relation with the accumulation of unsuccessful treatments over time, in the sense that a perception of repetition and recursivity played a particular role in the development of exhaustion. In addition, accumulation and exhaustion could also be built on being affected by multiple impairments simultaneously, piling up multifactorial expressions of suffering:

> *Waking up is difficult, because all days are the same: from the bed to the wheelchair… It's been more than two months since I last left the house… Except for the emergency visits to the hospital… once or twice. After a half hour, the wheelchair is already uncomfortable. If you are laying down, you constantly need someone to move your feet… you try not to ask all the time: "Hey, just a moment, come here." You need help to eat. And at some point complete immobility will appear… […] no one has mentioned the tracheostomy yet, but I know it is around the corner, and I don't want it.* (E7, Spain)

> *Surgical screws, and then some plastic. I don't know what it's called. Implants to keep my back… And it didn't really help. So, at first, it was just there that it hurt. Now it's my kidneys that hurt. Where they operated on… the hernias, it hurts less. But it's my kidneys that are hurting. And then, since I don't have any more… I don't have any more… Spleen.* (PERS118, Switzerland)

In the case of pain management over time, one particular example that was mentioned in both datasets is that of chronic pain patients. They had been treated many times over the years, with different doses and follow-ups, and adapted to pain but without perceived improvement. Participants described living under constant, chronic physical pain, and expressed with great emphasis having trespassed what they could bear in terms of intensity and duration:

> *And it's mainly the pain, anyway. Which made me take [this choice]. Because I can't stand the pain anymore. I take too much, I have to take too many drugs to relieve it a little. Then another side of it starts. I have pain almost everywhere [laughs].* (PERS118, Switzerland)

> *In addition to daily and nightly pain, I also have extra pain attacks, and those are unstoppable. Don't go anywhere, don't take any pill because it only gets worse […] [Going to] the emergency room means getting a Voltarén [diclofenac sodium], an Enantyum [Dexketoprofen], pills that were mocking my pain. Leaving as I had entered, and having taken the car, with potholes on the road that were like blows, and then, scream and scream as a furious little animal.* (E11, Spain)

Due to its complexity, patients' perception of an impossible alleviation of symptoms made them question whether they were expressing their pain understandably, and they were worried that healthcare professionals involved in their care or in the evaluation of their assisted dying request may not fully grasp the severity of their suffering; patients perceived that this difficulty in expressing their pain could render parts of their suffering less visible to others, reinforcing feelings of being insufficiently understood or recognized in care relationships.

Hence, exhaustion could be intensified by trying to explain or articulate exactly how they were feeling:

> *People say, "Everything's fine, madam, you're fine!" That's what they say, but people don't realise that my body is in pain. They can't see that I'm suffering.* (PEREF105, Switzerland)

> *It is a physical suffering, obviously. But, of course, everything physical transcends to the emotional, cognitive, psychological. […] You become stiff in bed and… you even lose your discourse.* (E5, Spain)

Confronting dependency

Dependency emerged as another central concern significantly contributing to the experience of

unbearable suffering. Participants shared being concerned about losing their personal autonomy in the future. More specifically, they shared that maintaining the ability to perform daily activities independently contributed significantly to creating a sense of identity and self-worth, and the prospect of losing such abilities was described with profound apprehension:

> *Being dependent is [having someone doing] everything for me: prepare my medication, bring me my meals, but put them in the microwave and stay with me… or let's say I can't walk anymore, I'm in a wheelchair, or for anything else, the CMS [community health and social care centre] will come, etc. (…) And always needing more help and even more help, etc. I didn't want that. I want to leave while I am still in shape.*" (PERS1121, Switzerland).

In their accounts, the anticipation of future dependence on others emerged as a major source of distress. For many participants, this prospect was associated with losing the ability to care for themselves and having to rely on others for everyday and intimate activities. Most notably, participants expressed fear of a complete loss of bodily functions that would prevent them from performing even basic tasks, such as moving, eating, or reading, independently. Although the participants rarely used the term *dependence or burden* explicitly, they often described being particularly distressed about relying on others for intimate needs, including toileting or bathing, which was described as particularly distressing:

> *I don't want to get to that point… Having someone cleaning me, bathing me. For me, that goes against what it means to be a human being.* (E14, Spain)

Participants expressed significant concern that such a situation would inevitably arise in the future; thus, the prospect of foreseeably having to endure it in the future was already experienced as an unbearable form of suffering. They shared with great determination the will to avoid this situation at all costs. However, for some participants, this prospect had already become a reality, with the onset of severe and ongoing physical deterioration. They described an increasing need for caregiving and external assistance to accomplish basic activities:

> *I am very independent, and [now] I can't even shoo away a fly anymore…and it gets worse and worse. Your hand gets twisted, you can't eat on your own; you become deeply dependent, and you suffer a lot.* (E6, Spain)

> *A month ago, I lost my independence. This means that what I never wanted has now happened, namely that I can no longer serve, but I have to be served.* (PERS3102, Switzerland)

Such accounts conveyed the difficulty of recognizing that dependence was no longer an anticipated possibility but had become an immediate lived experience. In these situations, participants reported suffering from emotional difficulties to cope with their increasing need for assistance and support, and they reported the difficulties of talking with their loved ones openly about it:

> *As I am now, I am a problem, and I will become an ever bigger problem. I can't tell her [the wife] this, huh? because she always says: 'I don't want you to do anything for me'. You know what I mean? I can't mention it to her, but this is one important reason.* (E4, Spain)

Most participants with families described with great discomfort how caregiving responsibilities were increasingly assumed by their relatives, leading them to perceive both their own suffering and that of their families as intensified by the exhaustion caused by their dependence:

> *I want it over because of the pain. For me, above all. But also for them, so they can rest—especially my husband, he deserves to rest.* (E9, Spain)

Participants, thus, explained that unbearable suffering was also experienced in the fear and discomfort of an increasing dependence, which would not only make them suffer, but could also affect their relatives, as they would need to adopt the main caregiving role.

Erosion of personhood and sense of identity

Participants described experiencing a degradation of their sense of identity driven by progressive disease-related deterioration, which resulted in no longer recognizing themselves or having the feeling of being recognized by others. They expressed that their health deterioration affected all areas of their lives, which placed them in a state of continuous mourning of the Self. Mourning for their past selves, for who they were and are no longer, contributed to experiencing suffering as unbearable. This feeling was also exacerbated by their expectations for and anticipation of further physical deterioration. As a participant has put it:

> *A degenerative disease is difficult to cope with because it forces you to deal with mourning your own reality, your quality of life, your life, constantly. It affects all aspects of your life: personal, family, social, work, economic and professional.* (E8, Spain)

One regularly mentioned example of an element contributing to the mourning of the sense of Self was the degradation of their physical appearance. Participants mentioned that seeing their personal appearance degrade was emotionally challenging as they no longer recognized themselves and felt that this new appearance did not reflect their personal sense of identity:

> *What you see is not me, that is the most important. I am myself on the inside but not on the outside. […] I went from being a person like you to being what you see.* (E6, Spain)

> *I mean, my teeth are rotting, I look like a junkie, I'm losing them, I have a hole inside me. I mean, I was already unwatchable, I was pitiful before.* (PERO108, Switzerland)

> *Over the next few weeks, it's going to be more chemo, more radiation to the brain. Both of them tell me I'm going to lose my hair, I'm going to be very weak, I don't feel well, I'll be honest with you. If I physically break down, if I realise that it really affects me losing my hair, it's stupid because it's… I mean, basically, I don't think it's a big deal to lose my hair, but it's the fact that all of a sudden it's noticeable, that when I look in the mirror, I see that I'm sick. Up to that point, it's okay, I have lots of scars, etc. But when I look at myself, I still recognise myself.* (PERS1112, Switzerland)

In addition, some participants stated that a sense of Self was built on the ability to engage in meaningful daily activities and to do so independently; the growing need to rely on others for care was perceived as conflicting with their core values and principles, leading to a perceived loss of dignity, independence, quality of life, or meaning:

> *I don't do anything anymore. I can't even ride my motorcycle because I don't have the fingers to squeeze the clutch. I mean, if I had a future… I would have modified it so that I could use it. I can use it because it's a '49 Harley, so it's a bit complicated. But I would have fixed it up so I could use it. Instead, now I don't do anything anymore.* (PERO104, Switzerland)

> *And now that I feel that my health is deteriorating and that I can no longer work with this computer, I am a creative person, in fact, and I can no longer create. As a result, I feel like I'm no longer of any use.* (PERS112, Switzerland)

Finally, participants expressed that they were no longer able to make efforts in sustaining relationships. The deterioration also impacted their abilities to engage in social activities and caused some participants to feel isolated. Isolation was further referred to as a distancing from others (a reduction of human contact) but also a capacity to contribute to and fulfill their personal role in society. Losing these abilities and roles intensified their experience of unbearable suffering:

> *I've virtually had to break up with a lot of people because they were stealing my energy. Most of my friends, although not all, come from other countries and, for them, all this story sounds very bizarre, so to speak; they don't really understand what is happening to me and I was wasting a lot of energy because they were always questioning me, asking me questions. In the end I said: 'Look, for the sake of my wellbeing I'm going to end this relationship. People drain my energy and I don't have much energy. When you are not ok, your energy is very low… I had to stop seeing them.* (E5, Spain)

> *Your situation, your suffering gets to a point that you ask yourself: is this life? No. Not anymore. Besides loneliness…* (E8, Spain)

Hopelessness and loss of purpose in life

Hopelessness captured participants' loss of confidence that the future holds any positive prospects. It was closely linked to a loss of purpose and meaning in life, as participants described feelings of uselessness, weariness of living, and the perception that life under such conditions no longer constituted a feeling of living a "complete" life. Beyond the loss of their ability to engage in meaningful activities, participants described having lost their inner motivation or will to continue experiencing or engaging in activities that once brought joy or fulfillment:

> *When you lose all motivation. Living without motivation is the antithesis of life. We are somehow programmed to live, and… the human mechanism is motivation; if you lose it… if they erase it, it is not just that life becomes insipid…It hurts…* (E3, Spain)

> *Before, I used to go everywhere, shopping, hiking in the mountains, in the forest… I had a normal life, which was extraordinary for my age. And now, all I have is my age. […] You lose that flame, the flame that makes you live, you don't have it anymore. So then, you don't want anything anymore. There's no point anymore. It's exhausting. Then the lady who came said that everyone was the same. They had this kind of exhaustion because we lost the spark that sustained us, that made it our life. And now, it's more than just waiting. It's forcing yourself to live. That's it. It's not living anymore, it's surviving.* (PERS1130, Switzerland)

Participants described how this loss of motivation, together with the progressive deterioration, made planning for the future feel pointless, as they believed it was already "too late" to enjoy anything. Many expressed hopelessness, expecting continued losses

and a worsening future, with little or no expectation of improvement:

> *Suffering is greater than anything you can do… and ultimately all you've got left is an even worse suffering, because the illness won't stop here; and even if it did, I already don't want to live like this. It is going to hurt me, to bother me more and more, I will deteriorate more and more.* (E8, Spain)

> *At my age, I have no more hope of having anything but good things or bad things. In any case, I'm going to avoid the bad things. Because the good things, I don't know, I don't know where to put them, but the bad things, they're going to come. I don't know if it'll be tomorrow or the day after tomorrow, but they're going to come. So why wait?* (PER0107, Switzerland)

> *To… to wake up in the morning and not expect anything. Do not expect anything good. That's it. Do not have a reason to live, do not expect anything…and if something comes, it is just pain*. (E4, Spain)

Participants' lack of future expectations undermined their perceived ability to sustain hope, with some noting that the chronic and recurrent nature of hopelessness intensified its impact over time. The loss of life purpose, combined with anticipating only further deterioration and loss, constituted a central dimension of unbearable suffering, as participants experienced distress both from what had already been lost and from the expectation that this loss would continue to deepen.

Fear of not being able to die when needed

This idea illustrates the fear of not being allowed to die when they perceive dying as the only bearable alternative to their life. Living, in general, has become overwhelming and transformed into a relentless source of suffering.

During the interviews, participants repeatedly described feeling that they were no longer truly living, but merely surviving. Consequently, they reported experiencing unbearable suffering because they were simply alive, accompanied by a profound sense of powerlessness and entrapment in a life, and they feared being forced to continue living like that:

> *To keep living like this is a nightmare; I can't give any more. I want to end… not my life in itself, but unfortunately, to end this situation, I need to end my life* (E8, Spain)

> *Because I can last a few more days. If I want to. But no, thank you. I've made enough effort to survive. I can do without it now… That's it.* (PERS1125, Switzerland).

Participants perceived that the alternative options offered to them were inadequate or intolerable, as they did not offer sufficient relief. Dying through assisted dying was thus portrayed as the culmination of a conscious, self-determined choice rather than as an act of surrender. The prospect of not being able to access death, and therefore having to continue living, became, in itself, a dimension of unbearable suffering. Participants expressed fears of being kept alive against their will, having their assisted dying requests rejected, enduring a prolonged existence without relief, and continuing to suffer while waiting, without purpose, for death to finally arrive:

> *Anyone who is not able to understand that someone is suffering so, sooo much that they want to die! And they want to die right now… Those people are not legitimized to make any decision… Because, in the end, what are these people doing? They worsen my suffering.* (E3, Spain)

> *You are not in their skin to feel their suffering. You can't just say: 'No, you must keep living like this'.* (E5, Spain)

In this perspective, death is perceived as holding greater value than life, revealing a profound inversion of meaning. Participants explained that they once valued life, but only when life was worth living; they thus found that not being able to die according to one's perceived needs and values was an intolerable source of suffering, and even linked it with notions of losing one's dignity. Rather than an act of surrender, the choice to die is portrayed as a final act of self-determination when all other options have failed and therefore becomes a source of concern as participants expressed fear of not finding this relief.

Discussion

Our findings show that unbearable suffering was articulated by participants through several shared expressions: *exhaustion, accumulation of treatments and impossibility of alleviation; confronting dependency; erosion of personhood and sense of identity; hopelessness and loss of purpose; fear of not being able to die when needed*. According to them, the experience of unbearable suffering was rarely limited to a single aspect; rather, it emerged from a unique, personal combination of multiple expressions, which often led them to perceive that the only relief was an assisted death.

Beyond showing that similar patterns of expression emerged across the two settings, participants provided several additional insights into how unbearable

suffering is experienced and narrated by patients requesting assisted dying. First, it was described less as a fixed condition than as a process, shaped by repetition, accumulation, progressive deterioration, and the anticipation of further decline. Second, what appeared to make suffering unbearable was not only the intensity of symptoms, but the perception that the situation had become irreversible and that no meaningful improvement remained possible. Third, participants frequently articulated unbearable suffering through the erosion of selfhood: loss of autonomy, loss of valued roles, self-recognition, shrinking social worlds, and loss of purpose were central to their accounts. Finally, the experience of unbearable suffering often led participants to perceive assisted dying not as passive surrender, but as a deliberate attempt to achieve relief and agency, over an otherwise considered intolerable trajectory. Taken together, these findings suggest that unbearable suffering is best understood as a multidimensional and processual experience in which bodily, relational, existential, and temporal dimensions are deeply intertwined.

Patients' perspectives on unbearable suffering offer a more nuanced picture of this experience

Understanding unbearable suffering from a patient's perspective is crucial because it provides information on a key aspect that leads to an assisted dying request. Although unbearable suffering is usually acknowledged as a subjective experience, very little literature has focused on the expressions of unbearable suffering from people requesting assisted dying. Focusing on first-person narratives and collecting empirical data allowed us to better understand this complex phenomenon.

Our results are, up to a point, aligned with the scarce literature that empirically investigates experiences of unbearable suffering. The foundational work by Dees et al. (2011) showed that, in requests for assisted dying, unbearable suffering stems from medical, psycho-emotional, socio-environmental, and existential factors (Dees et al., 2011). They concluded that suffering becomes unbearable when patients feel their personal integrity and identity are profoundly threatened and perceive no hope for improvement.

Subsequent studies have generally confirmed the centrality of these dimensions in the suffering expressed by individuals, observing and expanded on how each of these contributes to unbearable suffering: Bos et al. (2021) found that individuals tend to identify physical factors as the most important contributors to a sense of unbearable suffering, yet when asked to define precisely what is unbearable, they often describe a combination of physical elements and existential concerns (Bos et al., 2021); Nuhn et al. (2018) showed that patients mentioned a mix of factors such as loss of autonomy and control over one's life, loss of quality of life, or loss of the ability to participate in meaningful activities, loss of purpose (Nuhn et al., 2018); Verhofstadt et al. (2017) studied the particular casuistry of patients with psychiatric illnesses and demonstrated that 'mental' factors were more difficult to bear than 'physical' ones, with participants describing a fluctuation in the intensity and duration of unbearable suffering (Verhofstadt et al., 2017).

As described above, unbearable suffering has been commonly understood as an experience grounded in four key dimensions: physical, psycho-emotional, socio-environmental, and existential. However, to better understand the 'unbearability' reported by requesters, we intentionally moved away from this traditional classification by focusing on the empirical and specific expressions considered unbearable, rather than on the dimensions affected. In this sense, descriptive empirical research offers a way of granting epistemic recognition to patients' perspectives on unbearable suffering as rooted in their lived experiences.

By shifting the focus directly to unbearability itself, we blur traditional distinctions between physical and nonphysical dimensions of suffering, as well as possible hierarchies in the development of suffering experiences. For instance, *Confronting dependency* may be understood as part of the socio-environmental dimension, but could also be part of the psycho-emotional, the physical, and the existential. Similarly, by considering physical pain within the metatheme *Exhaustion, accumulation of treatments and impossibility of alleviation,* we highlight the intertwinement of physical, psycho-emotional, and existential dimensions. Each metatheme therefore encompasses several classical dimensions of suffering. Although the experience of unbearable suffering remains deeply subjective, as our findings demonstrate through the unique combination of expressions reported by each participant, our results also show that, across socio-cultural contexts, patients refer to similar expressions to explain their suffering.

Not all metathemes need to coexist within the same person for suffering to become unbearable, and what appears to render suffering unbearable is not the number of expressions involved, but the perceived irreversibility of the suffering experience itself. This does not mean that any single experience mentioned within a metatheme, such as loneliness, should automatically broaden eligibility for assisted dying; participants described such experiences as embedded in a broader lived experience of deterioration and

progressive loss of what made life bearable to them. These findings should therefore not be read as stand-alone criteria, but as illustrations of the complexity, subjectivity, and contextual nature of unbearable suffering that require careful, context-sensitive assessment. These findings contribute to ongoing reflections on the understanding of unbearable suffering in the literature and reflections on potential ways to obtain relief from it. Daneault et al. (2023) have shown that some individuals experience relief from suffering through regaining a will to live, accepting or coping with illness and impending death, or receiving strong support and presence from relatives and healthcare professionals (Daneault et al., 2023); however, it did not specifically investigate experiences of unbearable suffering. Our study therefore offers a nuanced perspective on patients' accounts of possible forms of relief in this context, notably by suggesting that assisted dying may be perceived as a response to unbearable suffering and as the only acceptable way to end life and obtain relief. In addition, these empirical results raise normative and practical questions regarding unbearable suffering in assisted dying requests, particularly concerning its role as a formal eligibility criterion for access to the practice.

Unbearable suffering as a formal requirement

The importance of understanding unbearable suffering from the perspective of patients who request assisted dying lies in the fact that it constitutes a formal requirement to access the practice. If we circumscribe the potential normative directions of our results to the countries analyzed, both Spain and Switzerland define unbearable suffering as a requirement to access assisted dying, either directly in the legislation or through their medical guidelines.

In Spain, Preamble I of the LORE defines the aim of the law as "to respect autonomy and the wish to end one's life in a situation of a serious, chronic and incapacitating condition or of a serious and incurable disease, suffering an unbearable suffering that cannot be alleviated by means deemed acceptable by the person, what we call a euthanasic context" (Oficial del Estado, 2021). It also mentions "a context of suffering (…) that the person experiences as unacceptable and that cannot be mitigated by other means." Chapter 1, article 3.c, refers furthermore to "constant and unbearable physical or psychological suffering with no possibility of relief that the person considers tolerable," in the case of a serious and incurable disease, whereas article 3.b, refers to "constant and intolerable physical or psychological suffering for the sufferer." In all these cases, the emphasis is put on the person's experience and perception of suffering. It also emphasizes the impossibility of any other method to relieve it, which aligns with the idea expressed by our participants, illustrating that death is the only possible relief perceived to their current situation. On some occasions, it specifies that it has to be either physical or psychological; however, as we see in the five categories presented, what makes requesters' suffering unbearable is much more complex than labeling it "physical," "psychological," or "neither one nor the other." Finally, the law specifies that the "euthanasic context," which includes unbearable suffering, must be assessed by three external figures: the referent physician, the consultant physician, and an *ex ante* Guarantee and Evaluation Commission (GEC), to see whether the person meets the criteria to access the practice or not. One of the elements that the referent physician must explicitly fill in the official document after a death with assisted dying is defined in Chapter 3, Art.12.a.5: "the nature of that constant and unbearable suffering and the reasons why they consider that there were no prospects of improvement" (Oficial del Estado, 2021). Our findings show that patients themselves perceive suffering cannot be alleviated or improved in a meaningful way, despite the intensity or reason behind it.

Regarding Switzerland, Article 115 of the Swiss Penal Code decriminalizes assisted suicide, but does not provide any specific information related to the eligibility criteria. In need of some guidelines to support healthcare professionals in assessing individuals' eligibility to assisted suicide, the Swiss Academy of Medical Sciences (SAMS) issued a medical-ethical guideline called "Management of dying and death" that is important to our topic. According to these guidelines, one of the four requirements to access assisted suicide is "severe suffering," also mentioned as "intolerable suffering." Section 2.4. is devoted to suffering and its alleviation, in all end–of-life situations. In it, there is a short reference to intolerable suffering, which is defined as the one that appears when suffering cannot be mitigated or compensated to a new equilibrium: "if severe suffering is perceived as chronic or progressive and any hope of alleviation or resolution has been lost, it is often described as intolerable" (Académie Suisse des Sciences Médicales, 2021). For some patients, this intolerability can thus become permanent until death, as in assisted dying requests. Our findings align with this idea, as it shows that unbearable suffering can become an experience grounded in progression, exhaustion, and hopelessness extending over time. In addition, this section

mentions that there are no objective criteria for unbearable suffering and recognizes that, as suffering is subjectively experienced and "can only be designated as such by sufferers themselves," it can vary from one person to another "depending on the personality and the environment." Once again, this affirmation is aligned with the aims of this study, as we tried to explore unbearable suffering from the participants' perspectives with a bottom-up approach. Identifying these patterns provides valuable insights into how unbearable suffering is interpreted, assessed, and operationalized within legal frameworks.

Healthcare professionals and unbearable suffering

As a criterion for access to assisted dying, unbearable suffering involves some kind of external assessment (usually done by healthcare professionals, most of the time, physicians) to verify whether it is met or not in each request. Hence, the question is: what exactly is the role of healthcare professionals regarding unbearable suffering and what consequences may it have for people requesting assisted dying?

As the philosopher Santiago López Petit says:"The decision in which one decides when a life is not worth living cannot be captured in a logical structure" (López Petit, 2018), which illustrates that unbearable suffering remains a challenge to assess, particularly for healthcare professionals required to evaluate whether a patient's suffering meets the criterion established by legislation. To support healthcare professionals in these complex assessments, various tools have been created to identify or measure patients' experiences of unbearable suffering in accumulative terms, including brief qualitative analysis of patients' perspectives (Ruijs et al., 2009) and healthcare professionals' reports of symptoms (Bos et al., 2021; Henry et al., 2023). However, these scales, checklists, or tools have usually been created according to the traditional five dimensions of suffering, and are a commonly used methods to validate the existence of unbearable suffering in requests for assisted dying, while often prioritizing the physical dimensions of suffering. Additionally, they come with multiple challenges and question the role and implication of the assessor.

For instance, previous literature investigating healthcare professionals' assessment of unbearable suffering shows that healthcare professionals balance patients' descriptions of suffering with "their own perceptions of how they would feel in that situation and their own values and beliefs about what constituted a suffering that could justify euthanasia" (Pesut et al., 2021). Other studies have shown that patients and healthcare professionals do not understand and define unbearable suffering in the same way: Pasman et al. (2009), for example, conducted a qualitative study about ungranted assisted dying requests with physicians and their patients and reported that non-physical aspects were the most important factors of unbearable suffering according to patients, whereas physicians highlighted physical suffering as the main factor in patients' requests (Pasman et al., 2009).

Considering that doubts about the existence of unbearable suffering can have significant consequences such as difficulties in assessing the patients' experience and reaching consensus, or even denial of the request, some alternatives might come up: (1) assuming that unbearable suffering is intrinsically particularized and inapprehensible from the outside, which means that healthcare professionals should refrain from questioning the patient's experience of suffering (see the Colombian case in Table 1); (2) accepting that understanding someone's unbearable suffering is possible up to a certain point and committing to training healthcare professionals on how to do it (e.g., creating lists or frameworks of subjective casuistries to broaden healthcare professionals' perspectives, or focusing on moral qualities like attentive listening, empathy, moral competence, and so on). In both Spain and Switzerland, the second alternative has been chosen.

In the Spanish context, the law gives healthcare professionals the responsibility to assess whether the euthanasic context is met, and also demands that the referent physician evaluate the nature of suffering. Hence, unbearable suffering is considered an experience that can be assessed and evaluated. The situation in Switzerland is slightly different: in the Swiss medical-ethical guideline, while recognizing that "the extent and nature of factors leading to suffering can be assessed –at least partly– from the outside" (Art. 2.4), it also acknowledges that intolerable suffering is not objectively determinable and that "the physician cannot be required to make such a determination" (Art. 6.2.1). Nevertheless, based on the previous history and repeated discussions with the requester, it suggests that healthcare professionals can gain a partial and subjective comprehension of the patient's experience when assessing their unbearable suffering by taking "adequate care to gain an appreciation of the patient's concrete, individual situation, such as to render its intolerability comprehensible" (Académie Suisse des Sciences Médicales, 2021).

Across contexts, our findings show that participants often struggled to put their suffering into words and feared that those involved in assessing or responding

to their request for assisted dying, especially healthcare professionals, might underestimate, misrecognize, or fail to validate the depth of their suffering. Their accounts do not suggest that unbearable suffering is wholly inaccessible to others, but rather that its subjective and multidimensional nature may make it difficult to be recognized adequately, reinforcing feelings of being insufficiently understood in care. From this perspective, the role of healthcare professionals is to engage sensibly with how suffering is described, interpreted, and communicated by the person requesting assisted dying. When faced with challenging assessments, ethical analyses have called for better support for evaluators (i.e., physicians), including opportunities to reflect on their own values regarding death and dying, to build meaningful therapeutic relationships with patients, and to foster effective communication with both them and their relatives (Gupta & Blouin, 2022). Overall, a patient-centred approach and a requester-focused understanding of unbearable suffering may help healthcare professionals recognize that their role is to comprehend patients' own definitions of their suffering. Our findings could also enrich theoretical debates, policy-making discussions, and the development of training abilities to better accompany assisted dying requests.

Strengths and limitations

The relevance of this study lies in the way it reconfigures the notion of unbearable suffering by grounding it in the testimonies and lived experiences of individuals who actually face it and articulate it when making a request for assisted dying. As such, it helps make visible the complexity of unbearable suffering (its richness, multidimensionality and overlapping nature) as lived and described by patients themselves, rather than only as a legal or clinical category.

To our knowledge, this is the first patient-centered qualitative study to include a cross-national study on how individuals express unbearable suffering, and one of the few that have explored the features of unbearable suffering as experienced by patients requesting the practice. It enabled us to show that similarities and transnational patterns emerge when a bottom-up approach is taken when studying the experiences of patients. The cross-national comparison represents a key strength of the study and makes it possible to disentangle what is shaped by legal framing from what appears to be intrinsic to the lived experience of unbearable suffering. Thereby, it contributes to broader ongoing normative, ethical, legal and clinical implications in its assessment.

Although the present analysis focused on common patterns across the two datasets, some differences in expression were noticeable. Spanish participants often described their suffering in a more vivid and emotionally charged way, whereas Swiss participants tended to be more restrained in expression. These nuances can be crucial for understanding how unbearable suffering is constructed, expressed, and evaluated in different settings. However, these observations should be interpreted cautiously, as the study was not designed to explain national differences or their possible cultural, linguistic, clinical, or contextual influences.

In addition, our study did not examine potential differences across subgroups, such as age, diagnosis, or cultural backgrounds, nor did it analyze the occurrence, distribution, or evolution of metathemes across participants over time. Because our study aimed to identify the meaning of participants' experiences, participants may have attributed different levels of significance to each dimension and referred to different dimensions at different stages of their trajectories without this being systematically captured in the present analysis. This limitation should be considered when interpreting the findings. Future research could explore how unbearable suffering is articulated across different personal characteristics, trajectories, and socio-cultural or legal settings.

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Declaration of IA

During the preparation and revision of this paper, the authors used ChatGPT (free version 5-5), DeepL, and Grammarly only to improve sentences flow, and to correct grammar, spelling and coherence; the authors reviewed and edited the content as needed and take full responsibility for the publication's content.

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Data availability statement

Relevant anonymized patient data underlying the analyses, results, and conclusions reported in this paper are available upon reasonable request from the corresponding author. Researchers interested in accessing the data may contact the corresponding author to discuss possible arrangements, subject to approval and compliance with applicable ethical guidelines.

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