

Understanding why patients request euthanasia when it is illegal: a qualitative study in palliative care units on the personal and practical impact of euthanasia requests

Danièle Le Boul, Anne Bousquet, Aline Chassagne, Florence Mathieu-Nicot, Ashley Ridley, Elodie Cretin, Frédéric Guirimand*  and Régis Aubry*

Palliative Care & Social Practice

2022, Vol. 16: 1–11

DOI: 10.1177/
26323524211066925

© The Author(s), 2022.
Article reuse guidelines:
sagepub.com/journals-
permissions

Abstract

Context: Some patients in palliative care units request euthanasia regardless of legislation. Although studies have explored the reasons for these requests, little is known about the subjective, relational, and contextual repercussions for the patient.

Objectives: The aim of this study is to understand the purpose of euthanasia requests from the patient's viewpoint and their personal and practical impact.

Methods: We conducted in-depth interviews with patients requesting euthanasia, their family members, and health care providers in 11 French palliative care units. A thematic analysis of the data was performed.

Results: In total, 18 patients were interviewed within 48 h of the request being made; 1 week later, 9 patients were interviewed again. Five main themes emerged: assuming the possibility of transgressing the forbidden, a call for unbearable suffering to be recognized, encouragement to change clinical practice, reclaiming a sense of freedom over medical constraints, and imagining a desirable future for oneself.

Conclusions: A request for euthanasia appears to be a willful means to remove oneself from the impasse of an existence paralyzed by suffering. It creates a space for discussion, which promotes negotiation with patients on care practices and therapeutics, and strengthens patients' sense of autonomy. Investigating the relationship between the evolution of euthanasia requests within the palliative care setting could be beneficial. It is important to encourage health care professionals to adopt a readiness to listen by interacting with patients in a way that is not momentarily action-oriented but rather focused on proactive discussion.

Keywords: euthanasia, palliative care, request for euthanasia, terminal illness

Received: 8 July 2021; revised manuscript accepted: 26 November 2021.

Introduction

Regardless of the legal status of euthanasia, terminal patients cared for by palliative care teams often request from health care professionals (HCPs) that their life be terminated.^{1–9} An integral part of the definition of euthanasia adopted by the European Association for Palliative Care includes a person voluntarily and competently formulating a request themselves to a doctor (or other person).¹⁰ We reported previously that 9%

of terminal patients expressed the wish to die or hasten death, but only 3% of them were forthcoming in requesting euthanasia from HCPs.³ The distinction between the request for euthanasia and the wish to die or hasten death is subtle and not always clear in the literature.^{7,9} Twenty-five years ago, however, Chochinov *et al.*¹¹ already distinguished between patients in the last phase of their illness occasionally expressing a wish to die (nearly 1 in 2 patients), those expressing a serious

Correspondence to:
Frédéric Guirimand
Pôle recherche
et enseignement
universitaire 'Soins
palliatifs en société'
(SPES), Maison Médicale
Jeanne Garnier, Paris
75015, France.
frederic@guirimand.fr

Danièle Le Boul
Anne Bousquet
Pôle recherche
et enseignement
universitaire 'Soins
palliatifs en société'
(SPES), Maison Médicale
Jeanne Garnier, Paris,
France

Aline Chassagne
Clinical Investigation
Center (Inserm U1431),
University Hospital of
Besançon, Besançon,
France

Sociology and
Anthropology Research
Unit (EA 3189), University
of Bourgogne Franche-
Comté, Besançon, France

Florence Mathieu-Nicot
Clinical Investigation
Center (Inserm U1431),
University Hospital of
Besançon, Besançon,
France

Psychology Research
Unit (EA 3188), University
Bourgogne Franche-
Comté, Besançon, France

Department of Palliative
Care, University Hospital
of Besançon, Besançon,
France

Ashley Ridley
University Bourgogne
Franche-Comté,
Besançon, France

Elodie Cretin
Clinical Investigation
Center (Inserm U1431),
University Hospital of
Besançon, Besançon,
France



Philosophy Research Unit (EA 2274), University Bourgogne Franche-Comté, Besançon, France

Department of Palliative Care, University Hospital of Besançon, Besançon, France

Régis Aubry
Clinical Investigation Center (Inserm U1431), University Hospital of Besançon, Besançon, France

Department of Palliative Care, University Hospital of Besançon, Besançon, France

*These authors contributed equally to this work.

and pervasive desire to die (1 in 12), and those requesting euthanasia (1 in 200).

The concept of the wish to hasten death has been broadly addressed within the literature. An international consensus reached through a Delphi process defined it as a reaction to suffering, in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate their death.¹² Clearly, 'the proposed definition focuses on the desire or wish and not on euthanasia'.¹² Systematic reviews have explored the reasons, meaning, and function of such a wish, without specifically considering the group of patients expressing a clear request for euthanasia to HCPs.^{13–15} The wish to hasten death is complex, combining thoughts, desires, and intentions, but does not necessarily imply a literal desire to shorten life.^{7,16} Having a wish to hasten death does not always mean that a person will act on the desire to die.^{17,18} On the contrary, the demand for euthanasia generates the expectation for an effective response within a definite time span.

The reasons and motivations underlying euthanasia requests have been studied in several different legal contexts.^{4,9,19,20} When permitted by law, there is a possibility that such a request will proceed. It is the starting point of a complex interactive decision-making process between the patient and the care staff. The negotiation undergoes various phases and takes place regardless of whether the request is granted or rejected.^{8,21–24} But if the law prohibits euthanasia, then why do patients still request it? The objective of our study was to understand from the patient's viewpoint the purpose of these requests by analyzing their personal impact on the patient and the practical impact on their environment. This study aspires to contribute knowledge to this field and thus to improve clinical practice.

Methods

We performed a qualitative study using in-depth interviews following a hermeneutic phenomenological model.²⁵ Our study's results adhered to and are reported according to the consolidated criteria for reporting qualitative research.²⁶

Research team

The multidisciplinary research team comprised five women: three psychologists (A.B., D.L.,

F.M.N.), one sociologist (A.C.), and one philosopher (E.C.); and two male physicians (F.G., R.A.). All held PhDs and had experience in qualitative research. They were working in the field of palliative care and had previously collaborated on other research projects.²⁷ The physicians and psychologists also held clinical posts in palliative care units (PCUs). None of those conducting the interviews (A.B., D.L., F.M.N., A.C.) had any prior contact with the participants.

Setting and recruitment

From October 2014 to November 2015, we conducted a multicentric prospective study across 11 PCUs in two regions of France (151 beds total): 5 units in Bourgogne Franche-Comté (BFC) and 6 in the Paris Metropolitan Area (PMA). Patients who requested euthanasia, the HCPs receiving the request, and the patient's family members were all eligible for inclusion. The HCP notified the research team of the euthanasia request, and the patient was then contacted for inclusion. The researcher verified that this was an explicit request for euthanasia: requests were considered 'explicit' when they were made verbally using direct terms of reference such as 'give me an injection' or 'help me to end it all'. Patients were enrolled in the study if they were mentally and physically capable of being interviewed and if they had no severe psychiatric history. All study participants provided informed written consent. Relatives of the patient were included only if the patient gave oral consent for their participation.

Data collection

Two interviews with an estimated duration of 40 min were scheduled with each patient at 1-week intervals, one on the day of the euthanasia request (D1) and the other 7 days later (D7). We estimated that about 15 interviews would suffice to understand in detail the experiences of patients requesting euthanasia and attain data saturation. An interview guide for patients was drawn up based on a literature review, previous studies, and the researchers' knowledge and experiences.^{3,28,29} Prior to its finalization, the guide was discussed by the research team. The guide was organized according to themes, with the introductory open question, 'You have agreed to take part in this study regarding the request that you made to Dr X; could you tell me about it?' (see interview guide in English and French in Supplementary Materials 1 and 2). All interviews were recorded,

anonymized, and transcribed. Field notes written after the interviews described the interaction between the researcher and the patient and the conditions of the interview. Data are available from the corresponding author on request.

Data analysis

The thematic analysis was based on a phenomenological analysis, and we studied the phenomenon related to the euthanasia request using a dual interpretation process³⁰: the patient gives meaning to their euthanasia request based on their perception of reality and interpretation of events. The researcher then tries to understand from the patient's viewpoint how they interpret their experience of their euthanasia request. The researcher examines and questions all collected material to produce an interpretation of the request. The patients are themselves not fully aware of the purpose of their requests, but this aspect enriches the analysis of the phenomenon. We explored each situation in depth, always situating the patient in their context. To obtain important themes, we conducted a thematic analysis of each case then compared them with each other to perceive the differences and convergences. We performed the thematic analysis as described by Braun and Clarke.³¹ This approach was a four-step process based on different levels of inference, starting with descriptive codes and larger themes, progressively defining the themes and ending with conceptual categories.

The steps were as follows:

1. Transcriptions were coded by four interviewers and members of the research team; each transcript was assigned to two interviewers for independent analysis.
2. Interviewer pairs discussed their coding decisions with each other and with other members of the research team to reach a consensus regarding the initial themes.
3. Agreement was reached on the initial thematic map.
4. As the analysis progressed, the researchers refined the themes (agreeing on a revised thematic map) and discussed emerging analytical concepts.

Ethical considerations

Ethical approval for the research protocol was granted by the regional ethics committee CPP

Est-II, Besançon (notification 14/439, 15 May 2014) and registered under national clinical trial number NCT02845817.

Results

Out of the 31 patients who had requested euthanasia and were referred to the research team, 30 met inclusion criteria. In all, seven patients were not invited to participate in the study due to their clinical condition, and five refused to participate. In total, 18 patients were included and interviewed on D1: 7 men and 11 women, with an average age of 76 years (38–95). In all, 12 had a cancer, 2 had amyotrophic lateral sclerosis, and 4 had other various diseases (Table 1). Of those interviewed on D1, only nine could be interviewed on D7, as six had died and three were too tired or disoriented to be re-interviewed. None of the 18 patients expressed suicidal ideation.

We identified five themes that can be seen as key dimensions of the role of euthanasia requests.

Theme 1: assuming the possibility of transgressing the forbidden

Although all patients were aware that euthanasia was illegal in France, some harbored various beliefs that it was nonetheless accessible. This evokes the possibility of transgressing the law. Some believed that it was already being performed discreetly, while others thought that it was a simple case of finding the right person to perform it out of compassion [‘The doctor, the last time I saw him, said when I was leaving: when the time comes, we’ll help you, and I was wondering ...’]. Pa (patient) PMA (Paris Metropolitan Area) 2. ‘I don’t believe the doctor would do it; but if he saw me passed out maybe, I dunno’ Pa PMA3]. Some patients likened palliative care to euthanasia because of the use of analgesics and sedatives and the decision to withhold certain therapies. They thought that PCUs would be the right place to benefit from euthanasia (‘I came for palliative care for that, it’s why I asked to come to palliative care’ Pa PMA6). According to these patients, legalizing euthanasia would put an end to the ‘hypocrisy’; the legal framework would ensure protection against possible abuses of the practice (‘I’m not saying it should be done systematically as there would be abuses ... grudges and settling old scores ... the way I see it, there’ll be revenge and retaliation, so the law is and isn’t needed’ Pa PMA3). At D7, patients’ statements

Table 1. Characteristics of patients and study conditions.

Patients having received information and consented to study	Place of recruitment	Sex	Age	Pathologies	HCP receiving request for euthanasia	Interview on Day 7
Pa BFC 1	PCU BFC 1	M	52	Amyotrophic lateral sclerosis	Doctor 1	Communication too difficult
Pa BFC 2	PCU BFC 1	F	69	Lung cancer	Doctor 2	Yes
Pa BFC 3	PCU BFC 2	F	70	Colon cancer, metastasized	Doctor 3	Yes
Pa BFC 4	PCU BFC 3	F	89	Colorectal cancer	Nurse 1	Deceased
Pa BFC 5	PCU BFC 2	F	81	Pulmonary cancer	Doctor 4	Deceased
Pa BFC 6	PCU BFC 4	M	81	Pulmonary hypertension	Nurse 2	Deceased
Pa BFC 7	PCU BFC 4	F	95	Gastrointestinal hemorrhage, polyarthritis, pain	Doctor 5	Yes
Pa BFC 8	PCU BFC 4	F	84	Breast cancer	Nurse 3	Yes
Pa PMA 1	PCU PMA 1	F	89	Esophageal cancer	Nurse 4	Yes
Pa PMA 2	PCU PMA 2	M	66	Breast cancer with brain, meningeal, and bronchopulmonary metastases	Doctor 6	Yes
Pa PMA 3	PCU PMA 1	M	92	Bronchopulmonary cancer	Psychologist 1	Yes
Pa PMA 4	PCU PMA 3	M	38	Neurodegenerative disease, diagnosed at 15 years of age	Psychologist 2	Yes
Pa PMA 5	PCU PMA 4	F	89	Bronchopulmonary cancer with pleural, bone, and bone marrow metastases	Doctor 7	Deceased
Pa PMA 6	PCU PMA 5	M	78	Cerebral infarct	Doctor 8	Too tired for interview
Pa PMA 7	PCU PMA 5	F	72	Amyotrophic lateral sclerosis	Doctor 9	Yes
Pa PMA 8	PCU PMA 5	M	75	Pharyngeal cancer	Doctor 8	Too tired for interview
Pa PMA 9	PCU PMA 2	F	68	Breast cancer with bone metastases, renal failure	Doctor 10	Deceased
Pa PMA 10	PCU PMA 1	F	80	Breast cancer, multimetastatic	Doctor 11	Deceased

BFC, Bourgogne Franche-Comté; F, female; HCP, health care professional; M, male; Pa, patient; PCU, palliative care unit; PMA: Paris Metropolitan Area.

indicated a shift in the emphasis of euthanasia requests toward requests for physician-assisted suicide, which is also illegal ('If they don't want to give me an injection, then they just have to give me something to drink and I'll swallow it' Pa BFC7).

Theme 2: a call for unbearable suffering to be recognized

The link between the patient's request to die and their relationship with their failing, suffering body was made explicit by their account of physical pain ('I suffered before, I suffered after. That, you

have to be there to believe it. And that was when I asked for euthanasia' Pa BFC3). The physical suffering originated from both acute episodes of symptom exacerbation and more chronic discomfort (such as dyspnea, fatigue, impaired function, declining mobility, and incontinence). Witnessing their body image transform and deteriorate caused profound distress ('Are you aware of the suffering? I never go out any more, everything is complicated ... I can't walk any more, I can't breathe, I can't speak, I can't eat ... I've seen myself age 30 years overnight' Pa BFC2). The suffering etched on the body in all its various forms induces a feeling of loss of control in several aspects of life. They all shared the feeling that life had become devoid of meaning. They expressed feelings of solitude tied to the feeling of hopelessness: the inability to share their suffering, the difficulty of communicating with or absence of loved ones, and a sense of uselessness ('I'm a middle-aged person who's had more than enough of this life – what am I going to do on this earth? I'll drag myself from one place to another ... useless, good for nothing, and I don't see what I'm here for' Pa PMA1; 'What I'm saying is, they're not in my shoes! But they just don't realize the suffering' Pa BFC3).

Patients' psychological distress manifested as fear, anxiety, shame, and a sense of guilt ('Perhaps I didn't fight hard enough (against the disease), perhaps I messed things up ... I can be mean at times, I'm not always caring ... I annoy people' Pa PMA1; 'Of course, who wouldn't be frightened? Once you reach the point where there's no hope left' Pa BFC3). A good number of patients expressed the fear of suffering in the moment immediately preceding death. Patients mentioned the threat of newly intensified symptoms such as pain or asphyxiation. They feared overwhelming, unbearable, and intractable suffering affecting all aspects of their being ('What really frightens me is the panic attacks and feeling suffocated, that can last minutes' Pa BFC2; 'I'm scared of going in terrible suffering' Pa BFC8; 'Yes because when the attacks come on ... you can do anything, nothing, because you're just suffocating' Pa PMA3). Some patients recalled painful memories of violent and unendurable suffering of their loved ones on their deathbed ('My grand-mother, I saw her suffocate to death' Pa BFC5). The decision to discontinue curative treatments led to a loss of hope for the patients. This hopelessness was at the heart of their mental suffering and exhaustion ('There's no hope left, and once there's no more

hope, why make people carry on living?' Pa BFC3; 'I don't want to have to make any more effort to bear what I've been going through for the past three years, I don't want to any more' Pa PMA2; 'It's just dragging my suffering out and making the meaninglessness of my life more apparent, I can't take it any more' Pa PMA4).

Theme 3: encouragement to change clinical practice

Of the nine patients who were able to partake in both interviews (D1 and D7), some perceived a change in their health care. They expressed satisfaction with the multidisciplinary care in the PCU as well as the support that they received from staff and volunteers. They felt reassured by the skilled pain and symptom management ('There is always someone here and if I call, well, someone brings me relief' Pa PMA3; 'Like the other time, I said straight away "I'm suffocating, I'm suffocating. Quickly, an injection!," as I know the injections give me, they gave me injections, immediately! So I didn't have ... it's very reassuring' Pa PMA3). They appreciated the attention received during nursing care and the concrete responses in the management of their daily life that gave them a sense of autonomy. For example, a paralyzed patient (Pa PMA4) had a call bell installed that was very sensitive to slight head movements thus allowing him to be able to call on nurses when needed; he had not benefited from this system during his previous hospitalizations. Patients also invested their relationships with the staff ('They (the nurses) bring closer ... They bring you closer to God ... a bit but I've, I've not got much time, that's the thing' Pa PMA2). These patients felt that they had been heard, acknowledged, and 'rehumanized' ('So that suits me fine ... because first I'll live more or less comfortably ... and above all my wishes are going to be respected (no therapeutic obstinacy)' Pa PMA5). Patients reported that this attentive response of HCPs could shift their view in regard to the urgency with which they felt their lives should be ended. Although they did not seem to withdraw their request for euthanasia, it was postponed or rather put on hold ('It's changed slightly, you see, when I first got here, in my mind, well I was thinking different things but the main thought was how to find the way of dying, life had become so unbearable for me ... I feel there's more consideration for me here as a human being in my own right' Pa PMA4).

Theme 4: reclaiming a sense of freedom over medical constraints

Patients' statements revealed a search for control over the moment and conditions of death. More importantly, they expressed a desire to break free from medical professionals' hold and the disease's grip on the body. Patients demanded freedom to think and make decisions for themselves, and for their decisions to be respected ('I aspire to a world where everyone can do what they want with their lives ... I think it's unfair and pretentious that it should be up to doctors to decide: no, you there, you remain alive, and hey, you there, you can leave, I don't like that one bit, I think it's really humiliating and disrespectful' Pa PMA5; 'I don't want others to decide for me ... but choosing to die fully aware, it's not other people's business' Pa PMA6). This self-proclaimed freedom to choose death might imply the patients' concern for others' freedom. Some patients express the wish to avoid being a burden to someone else and thus they feel the pressure to choose euthanasia ('I didn't want to burden someone else with that process because it's my business and my business alone, and as long as you're causing grief to others, you're no longer at liberty' Pa PMA6). Patients wished to relieve their relatives of this projected burden ('I thought, I'm just a burden to them now, what purpose do I serve?' Pa BFC6). The request for euthanasia coming from these patients was indicative of a life ethic grounded in values of autonomy and liberty. Their choice served that they had always been proactive decision makers:

'I said : "you know, my life has been based on individual freedom, that you don't step on anyone's toes, that people don't know what they're on about. So that, that's what comes from work and all that comes about obviously by choice ... So now, after this life of rich emotions, tenacity, enthusiasm, they come along when I've got an illness and tell me what to do." (Pa PMA7)

These patients recalled having always been courageous fighters in the face of adversity ('I've battled for years to recover but at the same time as I recovered, my physical condition deteriorated and a few months ago I looked at things straight on' Pa PMA4). They tried to assert their position on euthanasia without deviating from their religious or spiritual beliefs. Some patients who believed in God – practicing or not – sought to resolve the dilemma by attributing a value to euthanasia that was compatible with their beliefs,

be an act of love, or concealed it by talking humorously about their relationship with religion ('Relieving, that's not killing' Pa BFC3).

Theme 5: imagining a desirable future for oneself

Paradoxically, with euthanasia as a goal, patients were able to project themselves into a future where they would be relieved of suffering and anxiety while living in the present ('For me it's been a tough, crazy ride, all I've been put through in hospitals, that euthanasia would be like 'come on, let's move on, let's forget all this violence, and abuse, and misery, and let's think about another world ... a world which might be better? Perhaps, or worse, I don't know' Pa PMA4). Sometimes, there even emerged a certain pleasure in living ('Maybe you've heard I'm something of a chess player? I play quite often, there's one Mr P (volunteer) who came to play chess with me yesterday ... I gave him a run for his money ... that's comforting, isn't it' Pa PMA4). The majority of the patients found that being able to imagine a self-determined limit to their life course enabled them to reinvest the remaining time. They were able to temper their need for a response to the euthanasia request with the fact that the request opened up a space to negotiate with their HCPs ('So I said to him, "Dr you managed to persuade me (to eat), of this and that, protein packed granules of fairy dust! How did you pull it off? ... but for me, the patient, just to please and "not be stubborn", I'm going to persist in eating' Pa PMA7; 'Of course, yes, of course, there's no going back. I know but it's a salvation, to be relieved of the waiting, yes, the pointless moments during which, well, all you can do is just suffer' Pa PMA2). It was also propitious for initiating discussions with relatives ('Finding a place in the cemetery so I can rest I know where ... It's already an improvement. Well, It has to be taken care of, huh? If my husband won't take care of it, I ... I know he doesn't like dealing with things like that, now's the time to urge him to get on with it' Pa BFC2).

Discussion

This study aimed to clarify the reasoning underlying euthanasia requests. Our results highlight five purposes: assuming the possibility of transgressing the forbidden, a call for unbearable suffering to be recognized, encouragement to change clinical practice, reclaiming a sense of freedom over medical constraints, and imagining a desirable

future for oneself. These requests influence the subjective reality of patients and professionals, the objective reality of clinical palliative care practices, and the societal debate around end of life care.

Confusion between palliative care and euthanasia

The first important result of our study showed that patients requesting euthanasia within a PCU were unaware of or tended to ignore the difference between palliative care and euthanasia. Indeed, the euthanasia request is reasserted when its aim is to obtain medical help to die, and it is distinct from the wish to hasten death or an undetermined wish to die.^{7,9,11} A number of factors may contribute to the ongoing confusion between palliative care and euthanasia: the occurrence of death within a very short time span in PCUs, the use of morphine and sedatives, laws asserting the right to be relieved from unbearable pain, and the involvement of palliative care teams in the decision-making process following a patient's request.^{5,10,32,33} Whatever the legal context of euthanasia, the confusion between palliative care and euthanasia demonstrates the significant evolution of the societal representation of palliative care. Patients could come to consider PCUs as the place to seek euthanasia. In countries where euthanasia is illegal, the weakening symbolic strength of the law prohibiting it (i.e. according to patients, 'it is done even if it's forbidden') trivializes the subjective and social relationship with law violation and desacralizes the prohibition of murder.^{34–36} Whether or not euthanasia is legal, a death request while in palliative care cannot fail to raise questions about the discrepancy it introduces into the usual benchmarks and values at the core foundation of care.³⁷ It can lead HCP to ponder the significance of resorting to acts that are breaking or would break away from their work ethic and values. It requires them to recognize and name the reality of law violation if they want to 'maintain coherence within palliative care practices'.^{34,35,38}

Evolving patient–HCP relationship dynamic in the face of suffering

Second, euthanasia requests underline the need to recognize the unacceptability of living subjected to total pain.³⁹ The connection between unbearable pain and euthanasia request is documented but is not always decisive.^{7,8,20,41–43} The

request for euthanasia can constitute a call for help.^{44,45} If this is taken properly into consideration, it can decrease the overall suffering or even hinder the move to a suicidal act.⁴⁴ Furthermore, euthanasia requests call into question the care and support of PCU teams. When the euthanasia request leads to or influences a change in treatment, it reflects the patient's cry that the care they were receiving inadequately relieved their symptoms. For some patients, it is the rejection of a situation that has become intolerable where medicine is the decision maker of the end of life.⁴⁶ Medical activity is perceived as imposed violence that has been endured since the diagnosis and throughout the course of treatment. In this regard, the request for euthanasia widens the gap between the patient and HCPs and brings out the usual passive position of the patient toward the medical profession. As a result, the request for euthanasia may change the dynamic of the patient–HCP relationship. It can add meaning to the patient's role, becoming less passive through a two-way exchange. It opens the possibility for dialogue around care and treatment options, which takes into account the patient's desire for independence and control over the circumstances of their death where possible. Euthanasia requests, paradoxically, can reintegrate the patient into a relational network that seeks to respect their will.^{21,39} HCPs should be encouraged to listen carefully so as to deepen their understanding of the issues surrounding the request. Thus, the response to euthanasia requests is a less binary approach focused on momentary action (whether or not the act can be performed) but rather one engaged in supportive listening and patient interaction.⁴⁷ It is thus important for HCPs to be trained in accompanying these difficult discussions, to become able to proactively initiate them, and to build a trusting relationship with their patient.^{45,48}

Living in the present feeling recognized and rehumanized

Finally, our study participants who expressed satisfaction with their treatment and care in the PCU stated that they felt less overwhelmed by suffering or the fear thereof and that they had gained some control over themselves and their surroundings.^{49,50} For them, the possibility of a longer life course became more tangible and shifted the desire to die to a more distant time point. From this perspective, the oscillating desire for euthanasia would be better explained

by a patient's changing relationship with time rather than ambivalence between the desire to live and the willingness to die.^{7,51} The request for euthanasia plays a role in transforming the patient's present moment from that determined by passive waiting to that marked by the undertaking of a project, albeit an ending but nonetheless a seemingly reclaimed future.⁵² Moreover, an enhanced feeling of autonomy opens up the question of acknowledgment. As the surgeon Gawande states in his book, 'whatever the limits and travails we face, we want to retain the autonomy – the freedom – to be the authors of our lives. This is the very marrow of being human'.⁵³ Patients who perceive themselves as active participants of their life course and are acknowledged by their families and HCP as actors in decision-making consider themselves 'rehumanized' and essentially relieved of the burden of indignity and worthlessness.⁵⁴ The request for euthanasia appears here as a willful means to extract oneself from the impasse of an existence paralyzed by suffering.⁵⁵

Limitations and strengths

The following limitations of this study must be considered. First, the patients' fragile health affected the study period, limiting the number of interviews and thus the availability of data on the evolution of the euthanasia requests. Second, inclusion was dependent upon HCPs transmitting the request for euthanasia to the research team, and researchers had limited access to patients. This may have been a barrier to recruitment as patient selection was reliant on HCPs' interpretation and judgment. In terms of strengths, due to their poor health status, this study provides valuable insight of a palliative care population who are generally difficult to access and involve in research. The methodology was designed to minimize the risk of selection bias by diversifying the data collection sites (two distinct regions, 11 PCUs in six towns) and by allowing any member of a palliative care team to refer a request for euthanasia. Table 1 illustrates the diversity of the sources of referral, even within the same team, as well as the diversity of patients by age, sex, pathology, and recruitment site. Internal and external diversification ensured the robustness of participant selection and allowed us to consider a good level of information power as representative of reality.^{56,57}

Conclusion

A request for euthanasia appears to be a willful means to remove oneself from the impasse of an existence paralyzed by suffering. It creates a space for discussion, which promotes negotiation with patients on care practices and therapeutics, and strengthens patients' sense of autonomy. Investigating the relationship between the evolution of euthanasia requests within the palliative care setting could be beneficial. It is important to encourage HCPs to adopt a readiness to listen by interacting with patients in a way that is not momentarily action-oriented but rather focused on proactive discussion.

Acknowledgements

The authors thank all the patients, physicians, and nurses who participated. They especially thank Professor Serge Daneault (Montréal CA) for his useful feedback.

Author contributions

RA, DL, and FG were responsible for the study concept and design, obtained funding, and supervised the study. AB, DL, FM, and AC carried out the interviews and qualitative analysis. All authors interpreted the data. DL and FG drafted the manuscript. All authors critically revised the manuscript, read, and approved the final version of the manuscript, critically revised and corrected by AR.

Conflict of interest statement

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The work was supported by Fondation de France, Fonds pour les Soins Palliatifs, Défenseur des Droits, Fondation Bettencourt-Schueller, and Fondation le Chant de Étoiles.

ORCID iD

Frédéric Guirimand  <https://orcid.org/0000-0003-0767-9987>

Supplemental material

Supplemental material for this article is available online.

References

1. Ferrand E, Dreyfus J-F, Chastrusse M, *et al.* Evolution of requests to hasten death among patients managed by palliative care teams in France: a multicentre cross-sectional survey (DemandE). *Eur J Cancer* 2012; 48: 368–376.
2. Ferrand E, Rondeau E, Lemaire F, *et al.* Requests for euthanasia and palliative care in France. *Lancet* 2011; 377: 467–468.
3. Guirimand F, Dubois E, Laporte L, *et al.* Death wishes and explicit requests for euthanasia in a palliative care hospital: an analysis of patients files. *BMC Palliat Care* 2014; 13: 53.
4. Güell E, Ramos A, Zertuche T, *et al.* Verbalized desire for death or euthanasia in advanced cancer patients receiving palliative care. *Palliat Support Care* 2015; 13: 295–303.
5. Dierickx S, Deliëns L, Cohen J, *et al.* Involvement of palliative care in euthanasia practice in a context of legalized euthanasia: a population-based mortality follow-back study. *Palliat Med* 2018; 32: 114–122.
6. Chambaere K and Bernheim JL. Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience. *J Med Ethics* 2015; 41: 657–660.
7. Johansen S, Hølen JC, Kaasa S, *et al.* Attitudes towards, and wishes for, euthanasia in advanced cancer patients at a palliative medicine unit. *Palliat Med* 2005; 19: 454–460.
8. Emanuel EJ, Onwuteaka-Philipsen BD, Urwin JW, *et al.* Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. *JAMA* 2016; 316: 79–90.
9. Morita T, Sakaguchi Y, Hirai K, *et al.* Desire for death and requests to hasten death of Japanese terminally ill cancer patients receiving specialized inpatient palliative care. *J Pain Symptom Manage* 2004; 27: 44–52.
10. Radbruch L, Leget C, Bahr P, *et al.* Euthanasia and physician-assisted suicide: a white paper from the European Association for Palliative Care. *Palliat Med* 2016; 30: 104–116.
11. Chochinov HM, Wilson KG, Enns M, *et al.* Desire for death in the terminally ill. *Am J Psychiatry* 1995; 152: 1185–1191.
12. Balaguer A, Monforte-Royo C, Porta-Sales J, *et al.* An international consensus definition of the wish to hasten death and its related factors. *PLoS ONE* 2016; 11: e0146184.
13. Rodríguez-Prat A, Balaguer A, Booth A, *et al.* Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography. *BMJ Open* 2017; 7: e016659.
14. Monforte-Royo C, Villavicencio-Chávez C, Tomás-Sábado J, *et al.* What lies behind the wish to hasten death? A systematic review and meta-ethnography from the perspective of patients. *PLoS ONE* 2012; 7: e37117.
15. Bellido-Pérez M, Monforte-Royo C, Tomás-Sábado J, *et al.* Assessment of the wish to hasten death in patients with advanced disease: a systematic review of measurement instruments. *Palliat Med* 2017; 31: 510–525.
16. Crespo I, Rodríguez-Prat A, Monforte-Royo C, *et al.* Health-related quality of life in patients with advanced cancer who express a wish to hasten death: a comparative study. *Palliat Med* 2020; 34: 630–638.
17. Gerson SM, Bingley A, Preston N, *et al.* When is hastened death considered suicide? A systematically conducted literature review about palliative care professionals' experiences where assisted dying is legal. *BMC Palliat Care* 2019; 18: 75.
18. Rosenfeld B, Pessin H, Marziliano A, *et al.* Does desire for hastened death change in terminally ill cancer patients? *Soc Sci Med* 2014; 111: 35–40.
19. Evenblij K, Pasma HRW, van der Heide A, *et al.* Factors associated with requesting and receiving euthanasia: a nationwide mortality follow-back study with a focus on patients with psychiatric disorders, dementia, or an accumulation of health problems related to old age. *BMC Med* 2019; 17: 39.
20. Ruijs CD, van der Wal G, Kerkhof AJ, *et al.* Unbearable suffering and requests for euthanasia prospectively studied in end-of-life cancer patients in primary care. *BMC Palliat Care* 2014; 13: 62.
21. Dees MK, Vernooij-Dassen MJ, Dekkers WJ, *et al.* Perspectives of decision-making in requests for euthanasia: a qualitative research among patients, relatives and treating physicians in the Netherlands. *Palliat Med* 2013; 27: 27–37.
22. Dierickx S, Deliëns L, Cohen J, *et al.* Comparison of the expression and granting of requests for euthanasia in Belgium in 2007 vs 2013. *JAMA Intern Med* 2015; 175: 1703–1706.
23. Verhofstadt M, Van Assche K, Sterckx S, *et al.* Psychiatric patients requesting euthanasia: guidelines for sound clinical and ethical decision making. *Int J Law Psychiatry* 2019; 64: 150–161.
24. Li M, Watt S, Escaf M, *et al.* Medical assistance in dying: implementing a hospital-based program in Canada. *N Engl J Med* 2017; 376: 2082–2088.

25. Mak Y and Elwyn G. Use of hermeneutic research in understanding the meaning of desire for euthanasia. *Palliat Med* 2003; 17: 395–402.
26. Tong A, Sainsbury P and Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19: 349–357.
27. Leboul D, Aubry R, Peter J-M, *et al.* Palliative sedation challenging the professional competency of health care providers and staff: a qualitative focus group and personal written narrative study. *BMC Palliat Care* 2017; 16: 25.
28. Bousquet A, Guirimand F, Aubry R, *et al.* Palliative care unit caregivers facing a euthanasia request: a qualitative pilot study. *Méd Palliat* 2016; 15: 4–14.
29. Ly A-S and Aubry R. What lies behind a request for euthanasia or assisted suicide? A pilot study. *Méd Palliat* 2015; 14: 1–13.
30. Pietkiewicz I and Smith J. A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. *CPPJ* 2014; 20: 7–14.
31. Braun V and Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101.
32. Kreimeike K, Galushko M, Frerich G, *et al.* The DEsire to DIE in Palliative care: Optimization of Management (DEDIPOM): a study protocol. *BMC Palliat Care* 2018; 17: 30. DOI: 10.1186/s12904-018-0279-3.
33. Guirimand F. Continuous deep sedation until death: French recommendations. *EAPC Blog*, 2019, <https://eapcnet.wordpress.com/2019/03/04/continuous-deep-sedation-until-death-french-recommendations/> (accessed 21 December 2020).
34. Jacquemin D, Pujol N, Aubry R, *et al.* La transgression : une expérience à penser pour construire la visée éthique de certaines pratiques cliniques. *Med Palliat* 2015; 14: 91–97.
35. Jacquemin D and Rodrigues P. Pertinence du recours au concept de transgression face aux nouvelles situations de fin de vie. *Ethics Med Public Health* 2015; 1: 424–430.
36. Folscheid MD. De la transgression à la provocation. Travaux de l'Académie d'Éducation et d'Études sociales, 2003, https://www.aes-france.org/wp-content/uploads/2020/01/1_-_d._folscheid_.pdf (accessed 17 December 2021).
37. Pesut B, Greig M, Thorne S, *et al.* Nursing and euthanasia: a narrative review of the nursing ethics literature. *Nurs Ethics* 2020; 27: 152–167.
38. Pesut B, Thorne S, Storch J, *et al.* Riding an elephant: a qualitative study of nurses' moral journeys in the context of Medical Assistance in Dying (MAiD). *J Clin Nurs* 2020; 29: 3870–3881.
39. Muskin PR. The request to die: role for a psychodynamic perspective on physician-assisted suicide. *JAMA* 1998; 279: 323–328.
40. Dees MK, Vernooij-Dassen MJ, Dekkers WJ, *et al.* 'Unbearable suffering': a qualitative study on the perspectives of patients who request assistance in dying. *J Med Ethics* 2011; 37: 727–734.
41. Dees M, Vernooij-Dassen M, Dekkers W, *et al.* Unbearable suffering of patients with a request for euthanasia or physician-assisted suicide: an integrative review. *Psycho-Oncology* 2010; 19: 339–352.
42. Pasma HRW, Rurup ML, Willems DL, *et al.* Concept of unbearable suffering in context of ungranted requests for euthanasia: qualitative interviews with patients and physicians. *BMJ* 2009; 339: b4362.
43. Ruijs CD, Onwuteaka-Philipsen BD, van der Wal G, *et al.* Unbearability of suffering at the end of life: the development of a new measuring device, the SOS-V. *BMC Palliat Care* 2009; 8: 16.
44. Ohnsorge K, Gudat H and Rehmann-Sutter C. What a wish to die can mean: reasons, meanings and functions of wishes to die, reported from 30 qualitative case studies of terminally ill cancer patients in palliative care. *BMC Palliat Care* 2014; 13: 38.
45. Kreimeike K, Frerich G, Romotzky V, *et al.* The desire to die in palliative care: a sequential mixed methods study to develop a semi-structured clinical approach. *BMC Palliat Care* 2020; 19: 49.
46. Rodríguez-Prat A and van Leeuwen E. Assumptions and moral understanding of the wish to hasten death: a philosophical review of qualitative studies. *Med Health Care Philos* 2018; 21: 63–75.
47. de Saint Aubert E. Introduction à la notion de portance. *Arch Philos* 2016; 79: 317–343.
48. Kreimeike K, Pralong A, Boström K, *et al.* 'Desire to die' in palliative care patients – legal framework and recommendations of the national evidence-based guideline on palliative care in Germany. *Ann Palliat Med* 2021; 10: 3594–3610.
49. Daneault S. *Souffrance et médecine*. QC, Canada: Presses de l'Université du Québec, Québec 2006.
50. Mak YYW, Elwyn G and Finlay IG. Patients' voices are needed in debates on euthanasia. *BMJ* 2003; 327: 213–215.
51. Ohnsorge K, Keller HRG, Widdershoven GA, *et al.* 'Ambivalence' at the end of life: how to understand patients' wishes ethically. *Nurs Ethics* 2012; 19: 629–641.

52. Nissim R, Gagliese L and Rodin G. The desire for hastened death in individuals with advanced cancer: a longitudinal qualitative study. *Soc Sci Med* 2009; 69: 165–171.
53. Gawande A. *Being mortal: medicine and what matters in the end*. London: Henry Holt and Company, 2014.
54. Mak YYW and Elwyn G. Voices of the terminally ill: uncovering the meaning of desire for euthanasia. *Palliat Med* 2005; 19: 343–350.
55. Ricoeur P. Becoming capable, being recognized. *Lecture Library of Congress*, 2005, <https://www.diplomatie.gouv.fr/IMG/pdf/ricoeur05eng.pdf> (accessed 31 January 2021).
56. Tobin GA and Begley CM. Methodological rigour within a qualitative framework. *J Adv Nurs* 2004; 48: 388–396.
57. Malterud K, Siersma VD and Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res* 2016; 26: 1753–1760.

Visit SAGE journals online
[journals.sagepub.com/
home/pcr](https://journals.sagepub.com/home/pcr)

 SAGE journals