






“Nothing Hurts Less Than Being Dead”: Psychological Pain in Case Descriptions of Psychiatric Euthanasia and Assisted Suicide from the Netherlands

« Rien ne fait moins mal qu’être mort »: La douleur
psychologique dans les descriptions de cas d’euthanasie et de
suicide assisté psychiatrique aux Pays-Bas

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Abstract

Objectives: Euthanasia and assisted suicide (EAS) of individuals with mental disorders is a growing practice in several countries, including the Netherlands. Here, we aimed to identify the most frequent dimensions of and associated factors to psychological pain, which has been associated with suicidality, in individuals undergoing psychiatric EAS.

Methods: An exploratory retrospective content analysis of the English translation of 66 digital case records of individuals who died by EAS in the Netherlands between 2011 and 2014 was performed. Nine standard psychological pain dimensions (irreversibility, loss of control, emptiness, emotional flooding, freezing, social distancing, narcissistic wounds, confusion, and self-estrangement), illness, and sociodemographic variables were evaluated by 2 independent raters using a premade data abstraction form (Kohen $\kappa > 0.8$ in all cases).

Results: The mean number of dimensions was 4.64 ± 1.20 (median = 5), out of 9. The most frequent dimensions were irreversibility, loss of control, emptiness, and emotional flooding, in decreasing order. Past treatment refusal and the mention of social connections in case descriptions were related to the higher number of psychological pain dimensions (4.89 ± 1.24 vs. 4.31 ± 1.07 , $P = 0.03$ and 5.05 ± 1.17 vs. 4.43 ± 1.17 , $P = 0.03$, respectively). Emotional flooding was the only dimension specifically associated with specific psychiatric conditions, namely posttraumatic phenomena and personality disorders.

Conclusions: Numerous psychological pain dimensions were detected in case descriptions of individuals who underwent EAS before the procedure. Subjective nature of the study precludes definite conclusions but suggest that future studies should explore psychological pain and the role of interventions targeting it in patients requesting EAS.

Abrégé

Objectifs : L’euthanasie et le suicide assisté (ESA) de personnes souffrant de troubles mentaux est une pratique en croissance dans plusieurs pays, dont les Pays-Bas. Ici, nous avons cherché à identifier les facteurs et les dimensions les plus fréquentes de la douleur psychologique qui ont été associés à la suicidabilité chez les personnes soumises à l’ESA psychiatrique.

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Méthodes : Une analyse de contenu exploratoire rétrospective de la traduction en anglais des 66 dossiers numériques de personnes qui sont décédées par ESA aux Pays-Bas entre 2011 et 2014 a été menée. Neuf dimensions standards de la douleur psychologique (irréversibilité, perte de contrôle, sentiment de vide, débordement émotionnel, inertie, distanciation sociale, blessures narcissiques, confusion, et repli sur soi), la maladie et les variables sociodémographiques ont été évaluées par deux juges indépendants à l'aide d'un formulaire préfabriqué d'abstraction des données (κ de Kohen $> 0,8$ dans tous les cas).

Résultats : Le nombre moyen des dimensions était de $4,64, \pm 1,20$ (moyen = 5), sur 9. Les dimensions les plus fréquentes étaient l'irréversibilité, la perte de contrôle, le sentiment de vide, et le débordement émotionnel, par ordre décroissant. Le refus de traitement passé et la mention de connexions sociales dans les descriptions de cas étaient liés au nombre plus élevé de dimensions de la douleur psychologique ($4,89, \pm 1,24$ c. $4,31, \pm 1,07$, $p = 0,03$, et $5,05, \pm 1,17$ c. $4,43, \pm 1,17$, $p = 0,03$, respectivement). Le débordement émotionnel était la seule dimension associée spécifiquement à des troubles psychiatriques en particulier, notamment le phénomène post-traumatique et les troubles de la personnalité.

Conclusions : De nombreuses dimensions de la douleur psychologique ont été détectées dans les descriptions de cas de personnes qui se sont soumises à l'ESA avant cette étude. La nature subjective de l'étude exclut les conclusions définitives, mais suggère que de futures études devraient explorer la douleur psychologique et le rôle des interventions qui la cibleraient chez les patients qui demandent l'ESA.

Keywords

euthanasia, assisted suicide, psychological pain, terminal care, suicide, consultant-liaison psychiatry

Background

The acceptance and use of state-sanctioned euthanasia and assisted suicide (EAS, referred to as medical assistance in dying in Canada) for life termination are steadily growing worldwide. In the Netherlands, the first country to legalize euthanasia, EAS accounted for 4.6% of all deaths in 2015.¹ Conversely, in individuals with mental disorders, EAS remains a rare practice (in the Netherlands, about 1% of all EAS cases per year).² However, the awareness and consideration of this option by patients,³ and the total number of granted cases are steadily growing, despite the lower probability of proceeding with EAS after the request by this population.⁴

In the Netherlands, the law requires that several due care criteria, such as irreversibility of the condition, capacity to make informed decisions, and unbearable suffering, are met for granting EAS.⁵ Unbearable suffering criterion has been described as a profoundly personal experience of an actual or perceived impending threat to the person's integrity or life that has a significant duration and a central place in the person's mind.⁶ This definition partly overlaps with that of psychological pain: a lasting unpleasant and unsustainable feeling characterized by the perception of inability or deficiency of the self and also of frustrated psychological needs and social disconnection.⁷ Orbach et al. operationalized psychological pain in 9 dimensions: lack of control, irreversibility of pain, emotional flooding, estrangement, confusion, social distancing, freezing, narcissistic wounds, and emptiness.⁸ Psychological pain describes a widely accepted transdiagnostic dimension⁹ with specific neurobiological bases^{10,11} and validated measurement tools.^{8,12} Moreover, psychological pain is associated with suicidality, independently of underlying mental disorders.^{13,14} On the other hand, there is no universally accepted definition or measure

of unbearable suffering, although it has been evaluated using qualitative research methods, and consequently no study has provided comprehensive explanation of the neurobiological basis of this concept yet.

Most arguments in the debate on psychiatric EAS are based on the specific psychiatric diagnosis that might influence the patient's decision-making capacity,¹⁵⁻¹⁷ and the lack of consensus about medical futility in these disorders.¹⁸ Understanding the different facets of psychological pain in individuals who are granted EAS might help to determine whether the person's suffering is truly without prospect of improving. However, psychological pain in EAS has never been studied. To address this knowledge gap, we carried out an exploratory study in which we determined the occurrence of psychological pain dimensions in the publicly available descriptions of patients who were granted psychiatric EAS in the Netherlands.

Methods

Study Population

The present study is a retrospective multiple case analysis. The study population and the data retrieval process were described previously.⁵ Briefly, the analysis concerned 66 digital records of individuals who died by EAS in the Netherlands between 2011 and early 2014 and that were identified as cases of psychiatric EAS by the 5 Dutch regional euthanasia review committees (Regionale Toetsingscommissies Euthanasie [RTE]).

In the Netherlands, any patient can inquire about EAS with their treating physician. If EAS is granted, the treating physician is usually supported by a Consultation on Euthanasia in the Netherlands¹⁹ physician who is specially trained to assist other physicians during the EAS process. Patients can request EAS from the End-of-life Clinic that is

specialized in providing EAS.²⁰ After the EAS, the physician submits a written report, which is reviewed by 1 of 5 RTE committees, consisting of a physician, a lawyer, and a bioethicist. RTE committee evaluates the reports as well as other available information, including but not limited to patient journals and notes of the treating psychiatrist, and decides whether the physicians complied with the due care criteria for EAS. To increase transparency and inform guidance, RTE publishes a selection of detailed reviews (available at <https://www.euthanasiecommissie.nl/oordelen>).

Given their controversial nature, the majority of psychiatric cases of EAS were published between 2011 and early 2014. However, after RTE changed their publication practice in 2014, their publication markedly decreased. Therefore, the time frame covered by the present study represents the period during which the summaries of most psychiatric EAS cases were published.⁵ Study participant consent was not needed, and we analyzed documents that were professionally translated in English, as previously described.⁵

Data Collection

Two independent raters (AL and RS) performed the directed content analysis²¹ of the case summaries following a previously prepared data abstraction form that included the 9 psychological pain dimensions (see data abstraction form in the Supplementary Material). Both raters were medical doctors with at least 2 years of practice in clinical psychiatry. The inter-rater reliability was very high (Kohen $\kappa > 0.8$) for all measures where it was applicable. After data abstraction by each observer, disagreements were discussed in targeted consensus meetings.

The data abstraction form was developed by one of the raters (AL). It was based on previous publications that examined the same study population and on the initial screening of the first 5 cases to understand what information is available. The form included sociodemographic and clinical variables as well as an original psychological pain dimension evaluation measure that was created for this study (Supplementary Material).

For the present study, psychological pain was defined as a chronic subjective experience of mental suffering, linked to the altered perception of the self over time. The self-rated Orbach & Mikulincer Mental Pain Questionnaire, which measures current and lifetime psychological pain,⁸ was used as the basis for the retrospective evaluation of the psychological pain dimensions. It was chosen because psychological pain measured by this instrument is dissociable from the negative emotions related to depressive and anxiety disorders and is specifically associated with suicidality.^{8,11}

The following 9 psychological pain dimensions of this questionnaire were included in the abstraction form: (1) irreversibility (the individual expresses the perceived impossibility of regaining normal functioning or not suffering); (2) loss of control (the patient feels unable to cope with the situation and fears the future); (3) emptiness (the patient

perceives life as meaningless and has no future goal or desire); (4) emotional flooding (the patient feels unable to keep emotions in control and is overwhelmed by affective states); (5) freezing (complete inactivity and feeling of torpor or inoperativeness); (6) social distancing (avoidance of social interactions, described as an active withdrawal from society or the claim of wishing to do so); (7) narcissistic wounds (the patient has feelings of abandonment or rejection); (8) confusion (the patient expresses difficulties in thinking clearly, concentrating); and (9) self-estrangement (the patient feels a drastic change of the self, being not real or not the same person anymore). The detailed description of each item is presented in the data abstraction form (see Supplementary Material). As the process leading to EAS can be lengthy, psychological pain occurrence was not evaluated at a specific time.

Statistical Analysis

Data were analyzed using the SPSS software (version 24.0; IBM Corp.). Categorical variables were described as frequencies and percentages, and continuous variables were reported with means and standard deviations. Given the descriptive nature of the study, ad hoc cross-tabulations without hypothesis testing were performed to compare categorical variables. For continuous variables, the Shapiro-Wilk test was used to check the sample distribution normality, and the Levene test for equality of variances was performed to check the homogeneity of variance when comparing mean values. Then, groups were compared using the *t*-test or a general linear model when equal variance and the normal distribution were assumed, and the Mann-Whitney *U* or Kruskal-Wallis test in all other conditions. The grouping variable was the sociodemographic or clinical factor, and the dependent variable was the number of psychological pain dimensions. Cohen *d* was calculated to measure effect sizes. To establish the interobserver reliability, the Kohen κ was calculated for each psychological pain dimension measurement but for the irreversibility dimension that displayed 100% agreement. The 2-tailed *P* value threshold for statistical significance was set at <0.05 . No statistical procedure was used to control for multiple comparisons because it was deemed too conservative for the exploratory goal of the present study.

Results

Patients Description

The patients' characteristics are presented in Table 1. The population included many women and older adults. The sample clinical complexity was confirmed by the high frequency of psychiatric hospitalizations, history of electroconvulsive therapy, comorbidity, and suicide attempts. The most common psychiatric conditions were depression and personality disorders. However, some patients had rare conditions, such as factitious disorder.

Table 1. Characteristics of the Evaluated Individuals.

Variable	N (%)
Sex	
Women	46 (69.7%)
Age group	
30 to 49 years	16 (24.2%)
50 to 69 years	29 (43.9%)
70 years and more	21 (31.8%)
Functional dependency ^a	31 (47.0%)
History of psychological trauma ^b	15 (22.7%)
Social contacts mentioned in the case summary ^c	
Yes	22 (33.3%)
No	44 (66.7%)
History of treatment refusal ^d	37 (56.1%)
Physical pain ^e	21 (31.8%)
Time from psychiatric disorder onset to EAS ^f	
Up to 20 years	24 (36.4%)
21 to 40 years	29 (43.9%)
More than 40 years	10 (15.2%)
Undetermined	3 (4.5%)
Time from first expression of desire for life termination to EAS ^g	
Up to 6 months	20 (30.3%)
7 months to 1 year	22 (33.3%)
More than 1 year	23 (34.8%)
Undetermined	1 (1.5%)
Lifetime psychiatric conditions ^h	
Depression	41 (62.1%)
Personality disorder ⁱ	25 (37.9%)
Anxiety disorders, other than PTSD	15 (22.7%)
PTSD or posttraumatic residua	13 (19.7%)
Psychotic disorders	9 (13.6%)
Somatoform disorder, including pain disorder	8 (12.1%)
Bipolar disorder	7 (10.6%)
Substance use disorders	6 (9.1%)
Eating disorders	4 (6.1%)
Autism spectrum	4 (6.1%)
Neurocognitive impairment	2 (3.0%)
Other, including prolonged grief, alexithymia, factitious disorder, dissociative disorder, reactive attachment disorder, kleptomania	8 (12.1%)
History of electroconvulsive therapy	26 (39.4%)
Number of psychiatric conditions ⁱ	
One	19 (28.8%)
Two	23 (34.8%)
Three or more	24 (36.4%)
History of institutional care ^k	58 (87.9%)
History of suicide attempt	34 (51.5%)

Note. EAS = euthanasia and assisted suicide; PTSD = posttraumatic stress disorder.

^aFunctional dependency was defined as needing continuous care (e.g., living in supervised settings, indications of constant support from health care or social system).

^bPsychological trauma was identified when terms trauma or abuse were used in the case summary.

^cMention of social contacts outside of treatment facilities was based on both patient reports and case summary, including the presence of family/friends during the EAS procedure.

^dRefusal to treatment was defined as having refused any treatment modality (pharmacological and nonpharmacological).

^ePhysical pain was defined as pain with an identifiable physical cause.

^fTime from first described psychiatric condition until EAS. As the duration from psychiatric conditions onset was typically described qualitatively and vaguely (e.g., "decades," "since adolescence"), approximations to decades and typical time of onset for the aforementioned conditions were used in unclear cases.

^gFirst expression of desire for EAS was not necessarily the formal, explicit request that led to EAS.

^hPresence of psychiatric conditions was based on both formal and informal (e.g., "depressed") terms in case summaries. For posttraumatic residua, past trauma played an important role in psychopathology, but the term PTSD was not explicitly used.

ⁱFunctioning problems related to personality structure were frequent, but vaguely described, therefore only cases with an explicit statement of personality disorder diagnosis were included in this item.

^jComprises all psychiatric conditions, including personality disorders.

^kIncludes both acute and chronic care.

Table 2. Psychological Pain Dimensions in the Summaries of Psychiatric Euthanasia and Assisted Suicide.

Psychological pain dimension	N (%)
Irreversibility	66 (100%)
Loss of control	55 (83.3%)
Emptiness	42 (63.6%)
Emotional flooding	39 (59.1%)
Freezing	31 (47.0%)
Social distancing	28 (42.4%)
Narcissistic wounds	21 (31.8%)
Confusion	16 (24.2%)
Self-estrangement	12 (18.2%)

Note. The table presents the frequency of psychological pain dimensions in case summaries.

Psychological Pain and Its Dimensions in the Case Summaries

In several cases, the terms “psychic pain,” “inner pain,” and “emotional pain” were explicitly mentioned. The mean number of psychological pain dimensions in each case was 4.64 ± 1.20 , with a median number of 5 (minimum 2 to maximum 7). The frequency of each psychological pain dimension is presented in Table 2. Irreversibility was present in all case summaries. The other dimensions identified by the 2 raters in more than 50% of case summaries were, in descending order, loss of control, emptiness, and emotional flooding. Self-estrangement was the least frequently detected dimension.

Relationship Between Clinical, Sociodemographic Factors, and Main Psychological Pain Dimensions

Analysis of the associations between the main psychological pain dimensions and psychiatric comorbidities showed that only emotional flooding (i.e., feeling unable to keep emotions in control, being overwhelmed by affective states) was more common in individuals with posttraumatic stress disorder (PTSD)/posttraumatic residua (92.3% vs. 50.9%, $P = 0.01$) and personality disorder (76.0% vs. 48.8%, $P = 0.029$), while it was less frequent in patients with bipolar disorder (14.3% vs. 64.4%, $P = 0.016$). Emotional flooding was also related to the number of psychiatric conditions (present in 42.1%, 43.5%, and 87.5% of subjects with 1, 2, or 3 and more psychiatric conditions, respectively, $P = 0.001$). Furthermore, the general model using personality disorder, PTSD/posttraumatic residua, bipolar disorder, and number of psychiatric diagnoses as covariates significantly predicted emotional flooding, $F(4, 61) = 5.51$, $P = 0.001$.

On the other hand, several factors that were not directly related to clinical diagnosis were associated with a higher number of psychological pain dimensions (Table 3). First, the mention of social connections outside treatment facilities was more frequent in case summaries where more psychological pain dimensions were detected, with a moderate

effect size (Cohen $d = 0.59$, $P = 0.03$). Particularly, confusion was more common in case summaries where social connections were mentioned compared with cases without this mention (40.9% vs. 15.9%, $P = 0.025$). Second, the number of psychological pain dimensions was higher in individuals with history of treatment refusal in the past ($P = 0.03$, Cohen $d = 0.50$). Moreover, emptiness was more frequent among individuals with treatment refusal history than those described as treatment adherent (75.7% vs. 48.3%, $P = 0.022$).

Other evaluated factors, such as history of suicide attempt, physical pain, history of institutional care, sex, age group, and functional dependency, were not associated with the 9 psychological pain dimensions or their frequency.

Discussion

To our knowledge, this is the first attempt to explore the different dimensions of psychological pain in individuals who requested and later underwent EAS. We found that many different psychological pain dimensions were present in most patients (median number = 5). Irreversibility was described in all cases, probably because the patient’s perception of irreversibility is a necessary criterion (although not sufficient) for EAS in the Netherlands. Patient and physician must conclude that there is no reasonable alternative in the patient’s situation. The 3 other dimensions present in more than half of case summaries were loss of control, emptiness, and emotional flooding. This demonstrates the multidimensionality of psychological pain in individuals who were granted EAS.

Currently, psychological pain is mostly described in association with suicidal behavior, to which it is independently associated.¹³ The present study revealed that individuals with mental disorders who requested and were granted EAS experienced various dimensions of psychological pain and also had frequent hospitalizations, past suicide attempts, social isolation, and personality problems. These are recurring findings in suicidal individuals.²² We could hypothesize that psychological pain is associated with a general idea of death and not just with suicidal acts. This is in accordance with a previous study that detected equal intensity of psychological pain in suicide ideators and attempters,²³ suggesting that psychological pain might represent a phenomenon associated with the wish to die. In support, in a study that used continuous measures of psychological pain dimensions in suicidal individuals, the scores of most psychological pain dimensions correlated positively with “attraction to death” and “repulsion by life.”²⁴

However, we have not found an association between suicide attempt history and psychological pain dimensions count. Several reasons could underlie this discrepancy. First, we cannot exclude that the specialists who wrote the case descriptions could have failed to mention some suicide attempt cases. Alternatively, patients could have failed to report this information from clinicians, especially if attempts were not followed by interactions with the health-care

Table 3. Association Between Sociodemographic, Clinical Characteristics, and Mean Number of Psychological Pain Dimensions

Variable	Mean Number of Dimensions \pm SD	P Value	Cohen d
Sex		0.95	.
Women	4.63 \pm 1.20		
Men	4.65 \pm 1.23		
Social connections ^a		0.03*	0.59
Mentioned	5.05 \pm 1.17		
Not mentioned	4.43 \pm 1.17		
Suicide attempt history		0.52	.
Yes	4.76 \pm 1.21		
No	4.50 \pm 1.19		
History of psychological trauma ^b		0.14	.
Yes	5.07 \pm .88		
No	4.51 \pm 1.26		
History of institutional care ^c		0.73	.
Yes	4.66 \pm 1.21		
No	4.50 \pm 1.20		
History of electroconvulsive therapy		0.49	.
Yes	4.77 \pm 1.24		
No	4.55 \pm 1.18		
Physical pain ^d		0.15	.
Yes	4.29 \pm 1.31		
No	4.80 \pm 1.12		
History of treatment refusal ^e		0.03*	0.50
Yes	4.89 \pm 1.24		
No	4.31 \pm 1.07		
Functional dependency ^f		0.41	.
Yes	4.77 \pm .99		
No	4.51 \pm 1.36		
Age group		0.98	.
30 to 49 years	4.62 \pm .15		
50 to 69 years	4.66 \pm .29		
70 years	4.62 \pm .16		
Number of lifetime psychiatric conditions		0.19	.
1	4.74 \pm .15		
2	4.30 \pm .15		
3	4.88 \pm .26		

Note. EAS, euthanasia and assisted suicide; SD, standard deviation.

^aExistence of social connections was based on both patient reports and case summary, including the EAS procedure, where relatives were often present.

^bPsychological trauma was identified when the terms trauma or abuse were used in case summaries.

^cInstitutional care includes both acute and chronic care.

^dPhysical pain was defined as pain with an identifiable somatic cause.

^eTreatment refusal was defined as refusing any treatment modality in the past.

^fFunctional dependency was defined as needing continuous care (e.g., living in supervised settings, indications of constant support from health care or social system).

Normality and homogeneity were not assumed in all comparisons.

* $p < 0.05$, two-sided.

system. Second, included individuals possibly represent an extreme end of the psychological pain spectrum. Orbach et al. have found that the difference in psychological pain rating between suicide attempters and nonattempters reflected the unique contribution of irreversibility, loss of control, and emptiness.⁸ In the present study, all individuals were reported to express irreversibility, whereas loss of control and emptiness were the second and third most commonly reported dimensions. Overrepresentation of these dimensions might have resulted in a failure to find an association between psychological pain and suicide attempt history in the present sample.

Regarding the main psychological pain dimensions and psychiatric conditions, the only positive association was between emotional flooding and personality disorders, PTSD, and posttraumatic residua. This finding reflects the generally observed inability to control affective states in personality disorders²⁵ and PTSD.²⁶ Intense inner pain, represented by dysphoric affects and cognitions, has been reported to be at the core of borderline personality disorder.²⁷ Emotional flooding could reflect the importance of affective component in personality disorders and PTSD, while suffering related cognitions might be a shared trait among many individuals seeking EAS. However, the general

lack of an association between the number of dimensions and the diagnosis is in accordance with a previous study, which has found that psychological pain, measured by the Orbach et al. scale,⁸ was similarly elevated in borderline personality disorder and depressive disorder.²⁸ This shows that psychological pain possibly crosses diagnostic boundaries, and treatment options to address psychological pain could be beneficial regardless of the diagnosis.

Although mental illnesses are not generally considered to be terminal diseases, they become so when the EAS request is granted. Focusing on psychological pain rather than on psychiatric diagnoses could suggest treatment options that might offer relief from insufferable psychological pain, but that are currently not emphasized in treatment guidelines, generally focused on the diagnosed disease. Several pharmacological and psychotherapeutic interventions that have been demonstrated to target pain processing and perception could be of interest. Putative pharmacological interventions include such substances as an opioid analgesic buprenorphine,²⁹ an mu-opioid receptors agonist tianeptine,³⁰ or increasingly popular ketamine.³¹ Social pain, which is a major constituent of psychological pain, has been shown to be reduced by acetaminophen and marijuana.^{32,33} Among psychological interventions, acceptance and commitment therapy, for instance, has been shown to reduce psychological pain.¹³ If future studies confirm both the role of psychological pain in EAS and the long-term efficacy of these interventions for psychological pain reduction, they could become potential treatment options for individuals requesting EAS and presenting with psychological pain. In this case, the assessment of irremediability might include trying at least one treatment that targets psychological pain as a last-resort option.

Interestingly, we found more psychological pain dimensions in case summaries where social connections were mentioned in relation to the patient's daily life or the decision to apply for EAS. This finding differs from the consensus that low social integration is related to suicidality.³⁴ Moreover, loneliness has been identified as a predictive factor of assisted suicide in Switzerland.³⁵ Several explanations are possible for this difference. First, this study concerned only individuals who underwent EAS who are different from suicide survivors. It has been demonstrated that in a Dutch end-of-life clinic, requests for euthanasia by single and childless people are less likely to be granted.²⁰ Social connections might act as a protective factor, but only up to when psychological pain becomes unbearable. The anterior insular response has been associated with psychological pain during social inclusion, suggesting that even during pleasurable social interactions there is a degree of impaired brain functional activity linked to psychological pain.³⁴ Second, some individuals might choose EAS also to protect their loved ones from the guilt and burden that could accompany their suicide or prolonged suffering. Finally, as the published care summaries contain very little information on the psychosocial and family histories, this finding could be an artefact.

A particularly worrying finding of the present study was that high number of psychological pain dimensions was associated with past treatment refusal. While legally physicians in the Netherlands are allowed to state that there is no alternative if the patient has refused all of the unused treatment options, clinically this could represent the failure to apply all reasonable means to alleviate suffering in these patients. Severe psychological pain might have undermined the disease management already at early stages through the past refusal of possible beneficial treatment options. Treatment refusal should be a well-informed decision based on the patient's intact ability to consider all possible outcomes of any decision. However, mental pain and suicidality have been associated with many cognitive function impairments,³⁶ including decision-making.³⁷ As treatment refusal in the Netherlands is often considered compatible with irremediability, psychological pain-related hopelessness could lead to faster treatment option exhaustion. For instance, only about 40% of all individuals and 49% of individuals with depressive disorders underwent electroconvulsive therapy, one of the most effective treatment options for major depressive disorder.³⁸

Limitations

The results of this study should be interpreted with caution. First, the choice of psychological pain measure, based on the Orbach and Mikulínek scale,⁸ does not necessarily reflect all existing debate regarding the concept of psychological pain. Second, only a minority of patients with psychiatric conditions are granted EAS in the Netherlands. The results cannot be generalized to patients who requested, but we not granted EAS, as we have no information about these individuals. Third, the retrospective exploratory design precludes any assumptions of causality. RTE reports are written to inform whether the due criteria were met and not to describe the complex psychopathology of individuals extensively. This might have affected the numbers of dimensions described.

Given the limited information available in some cases as well as possible judgment and coding by the RTE problems, the general evaluation was relatively subjective. For instance, the identification of existing social connections was based solely on their mention in the text, and connections that were not deemed important by the person who described the case might not have been included. It is also possible that only the social contacts that either are involved in EAS or surpass a certain quality or intensity threshold are mentioned. However, the Dutch RTE case summaries are the only representative, patient-level clinical descriptions of persons receiving psychiatric EAS.

Another limitation is a possible cohort effect. Due to the reasons mentioned earlier, the cases analyzed in the present study are from the period between 2011 and 2015. No major legislation changes have been made during or after this period, major characteristics of patients have not changed between 2015 and 2017 (article in Dutch).³⁹ However, the

popularity of End-of-Life Clinics, specializing in EAS, has been increasing since their foundation in 2012.⁴⁰ End-of-life Clinics focus more on the autonomous wish of the patient and have been reported to be less reticent in cases of mental suffering.²⁰ Therefore, although EAS in psychiatry remains a very rare practice, it is possible that the procedure has become more liberal.

Conclusions and Future Directions

To conclude, this study provides the first insights into psychological pain dimensions in individuals before receiving EAS. It appears that psychological pain is a prevalent phenomenon in persons receiving psychiatric EAS. Past treatment refusal and mention of social connections were related to higher number of psychological pain dimensions, whereas emotional flooding was the only dimension associated with specific psychiatric conditions and their number.

Cue to the highly subjective nature, the present study does not intend to give definite conclusions but rather points to a direction of future research and discussion. First, although difficult to perform, studies evaluating psychological pain before EAS could provide important information to determine medical futility. Furthermore, as psychiatric EAS is rare and psychological pain might be present in individuals with other underlying physical conditions, such as cancer,⁴¹ we propose that a rigorous and pragmatic evaluation of psychological pain should be performed in individuals requesting EAS for many different reasons and not just psychiatric EAS.

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Supplemental Material

Supplemental material for this article is available online.

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