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EMPIRICAL STUDIES

Relating to life and death a qualitative study of individuals with a long-lasting death wish related to unbearable psychiatric suffering

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ABSTRACT

Objective: This study describes the lived experiences of persons with a long-lasting death wish related to unbearable psychiatric suffering (DWUPS) regarding their relationship to life and death. The findings are evaluated considering existing literature on suicidality and euthanasia, with a particular focus on the humanistic-existential perspective.

Method: An open-ended data-gathering strategy was employed to elicit comprehensive descriptive information about the phenomenon from ten in-depth interviews, applying the method of generic descriptive-interpretative qualitative research.

Results: Persons with DWUPS experience difficulties in connection with others, with themselves, with the world and with life itself. Concurrently, they indicate new possibilities for nascent connection in relation to others by receiving support and being able to share their death wish. This can result in growth in relation to themselves, in allowing hope, meaning and new engagement in life. The desire to die manifests itself in a variety of ways, including a strong and persistent death wish, an ambivalent attitude, or a temporary suspension of their death wish.

Conclusion: The process of exploring the death wish can assist persons with DWUPS in accessing potential ambivalence between life and death, in regulating emotional distress and in bearing existential concerns related to the life-and-death-questions.

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Introduction

Persons with a with a long-lasting death wish related to unbearable psychiatric suffering (DWUPS) often endure extensive psychiatric care and continuous suffering (Verdegem et al., submitted). “Unbearable psychiatric suffering” is linked to severe, persistent mental illness (SPMI) characterized by chronic psychiatric disorders and significant psychosocial limitations (Zumstein & Riese, 2020). Emotional exhaustion from long-term healthcare deficiencies can lead to a pervasive sense of life being unworthy (Verhofstadt et al., 2017, 2021).

Reakiro, a Belgian care centre for DWUPS, integrates recovery-oriented care, presence theory, experiential-existential psychotherapy, and palliative care (Vanhie et al., submitted). It provides counselling, peer support, and space to discuss ambivalence around life and death. A two-track approach combining death wish exploration with recovery care is recommended (Vandenberghe, 2017). In addition to counselling at Reakiro, outpatient or residential psychotherapy is tailored to the care needs.

Suicidality and euthanasia

Research highlights parallels between psychiatric euthanasia requests and chronic suicidality (Nicolini et al., 2022). Suicidal ideation varies in intensity, duration, and character. Individuals with psychiatric illnesses are 10 times more likely to attempt suicidal acts or die by suicide than the general population (Bachmann, 2018). However, most individuals with suicidal ideation do not die by suicide, which may suggest that there is a possibility for the transformation of the death wish (Costa-Maia et al., 2021). Hewitt (2013) distinguishes between impulsive suicidal thoughts and acts, characterized by limited autonomy, and rational suicidal ideation, not induced from the mental illness itself, but from the person who experiences dealing with his illness as unbearable. Research provides some insights into the factors that are involved in suicidal ideation and behaviour. Joiner’s interpersonal psychological theory (2005) posits that the conjunction of *perceived burdensomeness* and *thwarted belongingness* predicts suicidal

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ideation. *Hope* may protect against suicidal ideation and behaviour (Ropaj, 2023). Davidson et al. (2009) found that hope is negatively correlated with burdensomeness and thwarted belongingness but positively correlated with the capacity to engage in suicidal behaviour. Although counter-intuitive, this suggests that individuals with higher levels of hope may set more challenging goals and face greater risks and pain. Hill and Pettit (2013) found that *relatedness, autonomy, and competence* were negatively associated with thwarted belongingness and perceived burdensomeness, which in turn, were positively correlated with suicidal ideation.

Klonsky and May's three step theory (2015) suggest that *unbearable psychological pain* and *hopelessness* lead to suicide ideation. As pain escalates, *connectedness* to loved ones or meaningful roles weakens, increasing ideation. If pain continues, ideation can lead to suicide attempts, influenced by pain or death habituation, personality, genetics, and by the knowledge and accessibility to lethal means (Klonsky et al., 2021).

A number of studies (Guo et al., 2023; Lew et al., 2020; Marco et al., 2017) identify the *presence of meaning* as a protective factor against suicidal ideation, highlighting the importance of accurate treatments. However, the relationship between *seeking meaning* and suicidality varies across the studies.

In Belgium and The Netherlands, persons with DWUPS can request psychiatric euthanasia or assisted suicide (psychiatric EAS). This process follows specific steps (Vlaamse Vereniging voor Psychiatrie, 2017). A literature review by Ricou and Wainwright (2019) highlights the tension between autonomy and the value of human life in euthanasia requests. While some individuals strongly long for death, others express ambivalence or request euthanasia to hear of their ineligibility, to (re)find meaning or restore hope (Verhofstadt et al., 2021).

Based on a literature review, Costa-Maia et al. (2021) posit that individuals dying by suicide or requesting psychiatric euthanasia often struggle to adapt to ongoing suffering. Ricou and Wainwright (2019) suggest that suicidal ideation and psychiatric euthanasia requests share conceptual similarities, as both often stem from prolonged suffering and the perceived burden placed on others. Suffering spans four domains: medically related suffering, suffering related to intra- and interpersonal relations, existential suffering, and a perceived endlessness of suffering (Pronk et al., 2021; Verhofstadt et al., 2017).

A wish to live versus a wish to die

Ambivalence is common in persons with SPMI with suicidal ideation (Bonnewyn et al., 2017; McAuliffe et al., 2007; O'Connor et al., 2012). Fostering reasons to live is crucial, not only to counter the death wish, but also to reduce the internal struggle in the ambivalent person (Corona et al., 2013). In individuals requesting psychiatric euthanasia, ambivalence between life and death is also a key issue. A qualitative study by Verhofstadt et al. (2022) confirms the value of a two-track approach — as proposed by Vandenberghe (2018) - suggesting (1) giving space to the life track in the continuity of treatment and (2) taking the request for euthanasia seriously. However, the study of Verhofstadt et al. (2022) highlights the need of a flexible approach: for some persons, exploring the request for euthanasia increases their will to live, while for others it may discourage seeking alternatives to death.

Palliative psychiatric care

In cases where curative care for psychiatric disorders has failed, a palliative approach may be considered. Trachsel et al. (2016) define palliative psychiatry (PP) as an approach aimed at enhancing the quality of life for patients and their families who are dealing with the challenges of life-threatening severe persistent mental illness (SPMI). This is achieved by preventing and alleviating suffering through timely assessment and treatment of their physical, mental, social, and spiritual needs. The focus of PP is on harm reduction and the avoidance of burdensome psychiatric interventions that may have uncertain benefits. Palliative care complements recovery-oriented care by acknowledging treatment limits for persons with complex care needs (Decorte et al., 2020; Vandenberghe, 2018). Initial evidence suggests that better palliative care may reduce requests for psychiatric euthanasia (Barutta & Vollmann, 2015; Jansen van Der Weide et al., 2006).

Objective

The objective of this study is to gain insight into the lived experiences of life and death of individuals with DWUPS. A substantial body of research has been conducted on suicidality and euthanasia in the context of psychological suffering. However, to the best of our knowledge, there is a paucity of research that has been initiated from the perspective of the person with DWUPS (Pronk et al., 2021; Verhofstadt et al., 2017). The objective of this study is to provide individuals with DWUPS with a voice and gain insight in how they experience life and how they relate to their death wish.

Qualitative studies can refine, enrich or change existing theories where necessary by comparing the more general theory with observations in case studies, integrating the richness and specificity of the context (Stiles, 2017). In the discussion, the results are considered in relation to the broader frame of knowledge concerning the treatment of individuals with suicidal ideation or a request for euthanasia, with a particular focus on the humanistic-existential perspective. This facilitates the refinement of existing healthcare methodologies within this population, with suggestions for modifications in health care approaches where deemed necessary.

Method

Participants

Interviewees

This qualitative study employed semi-structured in-depth interviews. Individuals were all recruited from the Reakiro Center. All participants of the study were persons with a long-lasting death wish (several years or months) included in long-term care in Reakiro (1 to 1.5 year), combined with mental health care outside the centre (psychiatric and/or psychotherapeutic treatment). Individuals struggling with acute suicidality or with loss of awareness or volition were excluded from the study. All persons who met the criteria were informed of the study by their counsellor at Reakiro.

Elliott and Timulak (2021) suggest 10 to 12 participants, ideally added with two or three more, in order to reach saturation of the research findings. We planned and conducted ten interviews. The interviews took approximately one hour. Two interviews took place online, because of difficult access to the centre for two of the respondents. One participant dropped out before the interview took place because of acute exacerbation of the psychiatric symptoms. The interviews were conducted between 2021 and 2023. The research was approved by the Ethics Committee of University Hospital Leuven (UZ Leuven; S64625).

Researchers

The authors' psychotherapeutic approaches are informed by a synthesis of humanistic, person-centred and experiential-existential therapy frameworks. Researcher A, who was a clinical psychologist, an experienced person-centred, focusing-oriented and experiential-existential psychotherapist, and was familiar with persons with DWUPS, interviewed all participants and analysed the data. None of the participants were counselled by researcher A. Researcher B, a clinical psychology graduate student, conducted the co-analysis of the data and presented the initial findings in a master's thesis. The researchers affiliated with KU Leuven, University Psychiatric Center of KU Leuven, or the Reakiro Center were designated as Researchers C-E. Researcher F, professor of clinical psychology and psychotherapy at KU Leuven, participated in the analysis as a supervising expert-auditor and in the review of the manuscript as a co-reader. The manuscript was jointly reviewed by all parties.

Before data collection, the expectations and preconceptions were addressed in order to be mindful of these preconceptions during data analysis (Elliott & Timulak, 2021). The researchers anticipated the emergence of a range of expressions of a death wish. Furthermore, the hypothesis was formulated that the relationship to existential themes, such as a lack of meaning and connection, life anxiety and lack of agency, would play an important role in the experience of a death wish. However, no a priori assumptions were made regarding the interrelationships between these factors.

Analysis

To analyse the interview data, we used the method of generic descriptive-interpretive qualitative research (GDI-QR) (Elliott & Timulak, 2021), which is designed to study the lived experiences of the participants in psychotherapeutic and clinical situations. An open-ended data-gathering strategy was employed to elicit detailed descriptive information about the phenomenon of how people with DWUPS experience life and how they relate to their death wish.

In this method, critical realism (Barker et al., 2015) and dialectical constructivism (Elliott & Greenberg, 1997) form the philosophical and epistemological background. The tenets of critical realism posit that the veracity of any given assertion should be subject to intersubjective scrutiny. This is achieved through the application of consensus theory, seeking concordance between the findings of the different researchers, and the theory of coherence, corroborating observations manifesting consistency. Dialectical constructivism postulates that researchers should be regarded as active participants in the process of acquiring knowledge. The research is structured into distinct phases: pre-analysis, understanding and translating, categorizing and integrating. The process incorporates reflexivity and integrity checks.

Pre-analysis

A semi-structured interview was composed with the following questions to serve as a guideline: *Please describe your current experience of living. Please describe how you experience the idea of being death. Please indicate your current position in the process relative to your death wish. Please describe the process of dealing with your death wish you that you have gone through so far. What steps of the process did you go through (only questioned in case of euthanasia procedure)? What forms of support have been helpful during this process? What aspects of the process have you found to be lacking?*

Several steps were followed, as prescribed in the method of generic descriptive-interpretive qualitative research (GDI-QR) (Elliott & Timulak, 2021). First data collection took place. All persons that were counselled since 1 to 1.5 year in Reakiro were informed about the research. Individuals interested in participating got the information of the study and had one week time to consider participation. One of the nine participants dropped out because of a recurrence of severe symptomatology. Two more participants were recruited. The interviews were conducted by researcher A, transcribed verbatim by researcher B and revised by researcher A. In a second step of GDI-QR, the relevance of the gathered data concerning the research questions was determined and included. Thirdly, from the relevant data, meaning units were formed by researcher B and revised by researcher A. Meaning units are the smallest units of data containing complete thoughts, that are sufficiently developed to communicate a complete meaning relevant to one of the research questions.

Understanding and translating

Every meaning unit was summarized or abstracted to its *core idea* (Hill, 2012), representing the meaning in a concise manner. Implicit meanings are explicated by including the contextual information needed to understand the meaning of the unit by researcher B and revised by researcher A.

Categorizing

In a next step, categories were constructed separately by researcher A & B, by clustering the meaning units based on their similarities, naming and renaming them (C. E. Hill, 2012) via a process of constant comparison. The naming of the categories had to capture the shared meaning of the contained data. Equal involvement of each researcher is paramount and forms the basis of the trustworthiness and credibility of the study. To this end, the naming of categories belonging to meaning units was always first prepared separately and then compared between researcher A & B, until a consensus was reached. As the categorization stabilized, categories became our final findings. When saturation was reached, we moved from category construction to assigning new meaning units to existing categories, without modifying the categories. Subsequently, categories were hierarchically organized in higher and lower order categories. Finally, the whole process was audited by researcher F. Unclarities and disagreements were clarified in dialogue with researchers A & B, and a final renaming of the categories was implemented in consensus.

To provide a heuristic interpretation of the meaning of the categories within the sample, categories were characterized based on the frequency of appearance: when categories were reported in at least 80% of the cases, they were described as *general*, and as *typical* when they were shown by at least half of the participants. When at least two respondents reported a category, it was named as *variant* and a category only presented by one participant was called *unique*. The enumeration of the categories was not to emulate quantitative research but to provide a heuristic interpretation of the meaning of the category within the sample, contributing to the transparency of the analysis.

Integrating

After the process of categorizing, a visual model was designed which summarizes the results and puts them in a logical order and made relations between categories clear.

Reflexivity and integrity checks

To improve the quality of our research, we planned some methodological integrity checks to enhance the richness of the data, the accuracy of the transcriptions and the credibility of our findings. Transcriptions were conducted by Researcher B and subsequently reviewed by Researcher A. Triangulation was built into the study process by bringing in different perspectives on the data through the combination of an experienced and an inexperienced researcher together with a supervising expert-auditor. The consensus process is based on the principles of mutual respect and equal participation. The combination of a researcher with clinical experience in working with persons with DWUPS and a psychology graduate student, served to enrich insights and to provide an open-minded starting point for analysis. Subsequently, the expert-auditor (Researcher F), specialized in qualitative research and existential therapy was engaged to revise and give feedback.

Results

In this study, four men and six women are included. Table 1 gives an overview of the demographic and self-reported or clinically assessed psychiatric data of the participants. The average age was 45 years (SD = 8.47). All participants were Belgian. One of the participants was married, nine were single. One respondent had a graduate degree. Four participants completed an undergraduate degree, one was ongoing. Two participants completed high school, one respondent attended profession education, and one participant received special education. The educational level of one of the participants is unknown. Two respondents were working, seven were on long-term sick leave and one was incapacitated for work. Based on clinical assessment, referral information, and information obtained from patient anamnesis, on

Table I. Psychiatric diagnosis and place in euthanasia process of interviewees.

Participant		1	2	3	4	5	6	7	8	9	10
Psychiatric diagnosis	Mood disorders	x	x		x				x	x	x
	Trauma- and stress-related disorders		x					x			x
	Addiction disorders	x							x		
	Anxiety disorders			x							
	Personality disorders	x		x	x			x	x		x
	Neurodevelopmental disorders		x		x	x		x	x	x	
	Psychotic disorders						x				
Conditions of clinical attention	Suicidal behavior	x			x	x		x			x
	Suicidal ideation	x	x	x	x	x		x	x	x	x
Condition in procedure of euthanasia	Approval of euthanasia				x						
	In procedure, no approval for euthanasia					x		x	x		
	Wish for euthanasia but not in procedure		x	x						x	
	No current wish for euthanasia						x				x

average of 2.67 psychiatric disorders were diagnosed (Table I). Suicidal ideation and behaviour and condition in procedure of euthanasia are mentioned in Table I.

From our bottom-up research, two domains emerged: *Relating to death* and *Relating to life*. Within the domain of Relating to death, participants mentioned the *Experienced meaning of one's death wish*, *Relating to death anxiety* and *Fear of suicide*. Within the domain of Relating to life, participants responded *Problems in connecting* on the one hand and *Nascent connecting* on the other hand.

Relating to death

Relating to death is the second domain that emerged from the data, with on the one hand the *experienced meaning of one's death wish* and on the other hand *relating to death anxiety* (Table II).

Experienced meaning of one's death wish

Participants mentioned having an *early onset death wish*. They had a death wish since their childhood or their teenage years, or a death wish that lasted more than 20 years (interview 1, 2, 3, 4, 5, 8 & 10). They indicated that the death wish was permanent (interview 3, 5 &10) or hoped every night not to wake up anymore or hoped to die unexpectedly (interview 1 & 8). Participants experienced *death as a salvation from their suffering*. They saw death as a redemption of physical and mental suffering (interview 6, 7, 8, 9 & 10), a liberation (interview 2), and/or a way to find inner peace (interview 4, 8, 9). One respondent indicated experiencing the death wish also during periods when the psychiatric symptoms were less dominant, with the awareness that the symptoms would return (interview 7). One respondent spoke of death as a spiritual way-out, helping to heal from life (interview 9). Respondents mentioned the experience of a *determined, pressing death wish*. Some participants indicated explicitly not having any doubt about wanting to die (interview 1, 3, 4, 8). Respondents alluded that they were searching for other methods if their request for euthanasia would not be approved, feeling the urge of dying (interview 3). Participants articulated fear to be forced to put the death wish aside in psychotherapeutic programmes (interview 1), which led to avoiding new psychotherapeutic possibilities, or reported fighting daily against suicidal tendency and the yearning for self-harm (interview 4, 10). Participants expressed some *ambivalence towards one's death wish*. The intensity of their death wish was fluctuating. Sometimes they felt intensely preoccupied with death, while at other moments their death wish was less upfront or even absent (interview 2, 5, 6, 9 & 10). One participant mentioned the simultaneous presence of the death wish and the wish to live (interview 7), both experienced as attractive poles. As posited by one respondent (interview 10), the death wish was experienced as a paradoxical form of

Table II. Cross-analysis of the domain "Relating to death".

Domains/Categories	Participants										Frequency
	1	2	3	4	5	6	7	8	9	10	
Relating to death											
Experienced meaning of one's death wish											
Early onset death wish	x	x	x	x	x			x		x	Typical
Death as a salvation from suffering		x		x		x	x	x	x	x	Typical
Determined or pressing death wish	x	x	x	x				x		x	Typical
Ambivalence towards one's death wish		x			x	x	x		x	x	Typical
Abandoning death wish						x			x		Variant
Relating to death fear		x	x			x		x	x	x	Typical
Fear of suicide		x	x	x		x	x		x	x	Typical

safety and an exit strategy. This strategy was helpful to explore new opportunities, as it provided a means of escape when the opportunities in question failed to provide relief from suffering. Participants indicated to have *abandoned their death wish* (interview 6 & 9). One of them mentioned always having the possibility to turn back to it when living was again experienced as too difficult or when suffering would reach an intolerable level again.

Relating to death fear

Participants talked about their *relating to death fear*. Some respondents mentioned not being afraid of death (interview 3, 8 & 10). Some participants did not connect with being dead (interview 3 & 8). Participants expressed their death anxiety. For some, death anxiety was related to fear for annihilation or for their identity to disappear (interview 6 & 9). Some respondents searched some peace in spirituality to deal with death fear (interview 2 & 9).

Fear of suicide

Participants expressed their *fear of suicide*, fear for failure of the suicidal act (interview 2, 3, 9), wanting to save oneself from physical pain (interview 4) or lacking the courage to die by suicide (interview 5 & 6). Some respondents viewed euthanasia as a viable alternative to suicide, citing reasons such as avoiding pain, ensuring a peaceful death, or a lack of courage to die by suicide (interview 3, 4 & 5). By contrast, one person (interview 10) mentioned wanting to die by suicide, because "*death must be as destructive as life has been*".

Relating to life

Within the domain of Relating to life, respondents reported *problems in connecting, related to others, to themselves, to the world and to life. Nascent connecting* was mentioned *to others, to oneself* and *to life* (Table III).

Problems in connecting

Problems in connecting to others. Respondents mentioned *painful experiences in their attachment relationships*. They missed a foundation (interview 1, 7 & 9), security (interview 2, 9 & 10), peace and harmony (interview 8) or trust (interview 10) or lacked opportunities to develop (interview 9). Participants experienced a profound sense of loneliness during their childhood (interview 4 & 7), or lost an important attachment figure (interview 4, 6, 7 & 8). Some reported a profound sense of disorientation in the aftermath (interview 4 & 7).

> It was very normal for me that there was continuous arguing and violence. Not continuous, there were

Table III. Cross-analysis of the domain: Relating to life.

Domains/Categories	Participants										Frequency
	1	2	3	4	5	6	7	8	9	10	
Relating to life											
Problems in connecting											
To others											
Painful experiences in attachment relationships	x	x		x		x	x	x	x	x	General
Non-alligned care	x	x	x	x			x		x	x	Typical
Difficulties in connection to others	x	x	x	x		x	x			x	Typical
Feeling surrendered to professionals in relating to the death wish	x	x	x	x		x	x	x			Typical
Lack of support of relatives				x		x	x	x			Variant
To oneself											
Feeling mentally vulnerable	x	x	x	x	x	x	x	x	x	x	General
Persistent or unbearable suffering		x	x	x		x	x	x	x		Typical
Unprocessed traumatic- or loss experiences		x		x			x	x	x	x	Typical
To the world											
Not finding one's place or feeling alienated	x	x			x		x	x	x	x	Typical
Lack of recognition concerning mental vulnerability		x					x	x		x	Variant
To life											
Lack of hope or meaning	x		x	x		x	x	x	x		Typical
Groundlessness or not experiencing the right to exist	x	x	x	x			x	x		x	Typical
Lack of vitality	x		x	x		x	x	x			Typical
Nascent connecting											
To others											
Receiving support or recognition	x	x	x	x		x	x	x	x	x	General
Care for relatives	x	x	x	x			x	x	x		Typical
Being able to share the death wish	x		x				x	x	x	x	Typical
Experiencing growth in relation to others	x	x	x				x			x	Typical
Experiencing relational meaning			x			x					Variant
To oneself											
Experiencing growth in relation to oneself		x					x		x	x	Variant
To life											
Allowing hope and meaning		x	x			x	x		x	x	Typical
Engaging in life	x	x				x	x		x		Typical
Experiencing the right to exist										x	Unique

> some good moments. But there was always attracting and rejection with my parents. - Interview 2

Participants reported *non-aligned care*. They missed tailored care to their specific needs (1, 2, 3). Care is perceived as insufficient to reduce complex suffering (interview 7) or inaccessible related to the high cost (interview 3). Respondents demonstrated a degree of resistance towards recovery-oriented care, lacking recognition for their death wish, feeling unable to bear the effects of psychotherapy or lacking any positive effect of multiple former treatments (interview 1, 4, 7).

> In psychotherapy, I am confronted with very difficult experiences and things that are forbidden to speak about. I don't have the energy to do that. Coming home, I have to solve it myself … I also suffer a lot from dissociation there. My body reacts to what is said and that's not nice … – Interview 3

They lacked space to talk about their death wish, did not feel understood or carried by care providers (interview 3, 4, 9 & 10).

> My death wish was met with much panic, which put the lid back on the box of forbidden feelings for me. I got the feeling of none of this is really allowed … Nobody knew any solutions for it … I missed a safe space to turn to when I was struggling. I needed counsellors who could stay calm and mentalize.– Interview 10

Respondents experienced "*difficulties in connection to others*" in daily life. The challenge of allowing others often resulted in respondents isolating oneself while simultaneously experiencing a sense of solitude (interview 1, 4, 6 & 10). Participants talked about experiencing a suffocating feeling in contact with their relatives, because relatives reacted very protective out of fear of a possible suicide (interview 3, 4). They experienced many disappointments on a relational level (interview 6) or protected themselves by breaking-up with certain friends or being more selective in contacts, to facilitate their own act of dying (interview 2). Participants wanted to shield relatives for their death wish by withholding information, putting on a mask or keeping distance, because they felt the gravity of that given for the other (interview 2, 3 & 4). Feeling a radical defence against euthanasia in relatives, made it sometimes impossible to talk about it (interview 7). Participants indicated *feeling surrendered to the decision of professionals regarding their death wish*. Respondents perceived the procedure of the request for euthanasia as long and energy-wasting (interview 1, 2, 3, 4, 7, 8). Interviewees reported feelings of powerlessness in relation to the medical professionals, who were tasked with the decision of whether or not to allow them to die (interview 3, 4, 6). Respondents experienced a lack of acknowledgement by others concerning their death wish. They felt misunderstood in their death wish when euthanasia was not approved or considered by care providers (interview 3 & 8). Difficulties in finding a doctor for the performance or carrying out of euthanasia (interview 1, 3 & 7), the absence of the right to self-determination (interview 6 & 8), the uncertainty of the outcome of the process (interview 1) were all mentioned as stressful. The difficulties proved to be a significant impediment for participants, ultimately preventing them from initiating the euthanasia procedure (interview 2 & 8). Respondents indicated a lack of space to talk about their death wish or a *lack of support of relatives* in their present life, made them feel lonely or lost (interview 4, 6, 7 & 8).

Problems in connecting to oneself. Participants described experiences of *struggling with being mentally vulnerable*, which they identified as related to their psychiatric illness (interview 1–10). This vulnerability makes life very hard. Respondents also stressed the difficulty of dealing with limitations, linked to the vulnerability, e.g., studying, working, establishing relationships (interview 3, 6 & 9).

> I am disappointed in myself. I have not been able to live up to what other people expected of me.- Interview 5

Respondents indicated the continuous struggle with an inner critic voice (interview 1 &10).

> There is this critical voice in me that directly destroys everything. If I had a nice afternoon, that critic voice is immediately present afterwards by saying: but those people you were with, they didn't like you at all. - Interview 1

Participants mentioned *persistent or unbearable suffering*. They indicated how life is experienced as unbearable (interview 3, 4, 6, 8 & 9). More specifically, they described experiencing life as hell, being very unhappy, unable to bear the psychological pain anymore (interview 6 & 8), traumatic flashbacks in day-today actions (interview 4), or physical complaints (interview 3 & 8). Respondents mentioned how their suffering is persisting or even worsening (interview 3, 4, 6, 7, 8 & 9), suffering for a very long time, from childhood (interview 6 & 8), or living with the idea that life will always be difficult (interview 7). Participants found themselves unable to find inner peace (interview 2 & 4), feeling restlessness in their body (interview 2), feeling unable to sleep (interview 4), or experiencing inner conflict in decision making (interview 2). One respondent describes that despite experiencing significance, life feels still unbearable (interview 3). *Unprocessed traumatic- or loss experiences* were mentioned. Respondents described how growing up in an unsafe or unaligned environment, with a lot of conflict, violence, or transgressive behaviour, not feeling seen or accepted by their parents, not feeling at home, lacking security, feeling neglected or abandoned, missed opportunities in life because of the problematic home situation, is very difficult to deal with in life (interview 4, 8, 9 & 10). The processing of trauma is perceived as difficult. Participants indicated how losses had a major impact on their daily lives: not feeling able to bear the grief (interview 2, 4, 7 & 8) or being afraid of new connections (Interview 4).

Problems in connecting to the world. Participants described that they could *not find one's place or felt alienated to the world around*, feeling an outsider, or never had the feeling of belonging (1, 2, 5, 7, 8, 9 & 10). They expressed their dissatisfaction with society, which they experienced as very individualistic, cold, and sad. Respondents emphasized the *lack of societal recognition for their mental vulnerability* (interview 2, 7, 8 & 10).

Problems in connecting to life. Participants expressed a *lack of hope or meaning in life*. They experienced lacking meaningfulness or purpose (interview 6, 7 & 9), perspective in life (interview 1, 3, 6, 7 & 8), or feeling of not being of any significance (interview 9). One participant explicates how hoping is dangerous, because they can get disappointed (interview 4).

> At times when I am neither depressed nor hypomanic, I also think about euthanasia, not colored by emotions, but from a more objective knowing that life is always going to be difficult. – interview 7

Respondents *felt groundless or could not experience the right to exist*. Participants reported that their physical, emotional and attachment needs were not met in an attuned way. This has resulted in al lack of grounding, holding or feeling at home from childhood (interview 1, 2, 4, 7 & 10). They believed that something was thoroughly wrong with them, or felt they should not exist (interview 10). These experiences were typically already present in childhood and were subsequently reinforced in the context of their current lives. They mentioned how these feelings made it difficult or even impossible to be happy, or to build relationships with other human beings. Participants missed grounding after the loss of important attachment figures (interview 8), or by experiencing over and over that counselling programmes did not have any impact on their psychiatric problems (interview 3).

> I have never been accepted. My father always said I was not his child and that he did not want me.– Interview 1

Participants experienced a *lack of vitality*. Suffering was experienced as mentally and physically exhaustive, without any alleviating factors, often for a very long time. They struggled with daily tasks, because of fatigue or pain (interview 3 & 4). Respondents mentioned a lack of joy (interview 1 & 3), lack or loss of energy (interview 4 & 6), feelings of being burned-out inside (interview 3 & 8), or experienced being tired of life (interview 7).

Nascent connecting

Nascent connecting to others. Respondents mentioned *receiving support or recognition* from others as helpful. Recognition or presence from caregivers or relatives was experienced as supportive (interview 1, 2, 3, 4, 7, 8 & 10). In daily life, participants experienced support in doing things together with relatives or care providers, making them feel less lonely or feeling respected (interview 6 & 8).

> My counsellor sometimes takes me out for a drink somewhere. That's kind of cool because I used to get bullied. He is not ashamed to walk down the street with me. He doesn't care what other people would say about it. It's nice that he sees me as a human being and not as a fool. – interview 8

Participants mentioned feeling heard and understood in struggling with their death wish by care providers (interview 1, 3, 4, 6, 7, 8, 10) or relatives (interview 1) or being helped in their search for new possibilities in life. They felt supported by their counsellor in sharing the death wish with relatives (interview 3, 4). After sharing the death wish with loved ones, they experienced more support or recognition from relatives (interview 4, 9 & 10). In addition, the recognition of suffering and trauma from peers and patient-experts was helpful (interview 8, 9 & 10), feeling less alone and acknowledged in their deep pain. Furthermore, spirituality was perceived as a source of support (interview 6, 7 & 8). Finally, providing information about the process of declaration of euthanasia was also experienced as helpful (interview 1, 3). The respondents indicated a willingness to provide *care for their relatives*. They chose for euthanasia with the intention of preventing their loved ones from dying by suicide due to emotional or financial care (e.g., inheritance) (interview 1, 3, 4 & 9), allowing them to say goodbye (interview 9) or saving them from the trauma of suicide (interview 1 & 7). Besides, the desire to be present for significant others was an important reason for their continued survival for respondents (interview 2, 4, 8). Respondents mentioned the importance of themselves *being able to share their death wish* with care providers, with loved ones, or with peers (interview 1, 3, 7, 8, 9 & 10). One participant explained how the contact with peers, who recognized their pain, helped them to be able to share experiences that were potentially stressful to loved ones (interview 3).

"I wrote a letter to my sisters and my father about my death wish. Expressing my death wish to them was the beginning of asking for a little recognition. I never did that before…" – Interview 9

Participants perceived *growth in relation to others*. They facilitated the restoration of damaged interpersonal connections (interview 1 & 7), were more able to maintain the boundary between themselves and others (interview 2), were more authentic (interview 10), or could talk about the death wish on a more constructive level (interview 3). Finally, respondents mentioned *relational meaning*, the feeling of being significant for the other, to be helpful. Participants reported that they felt useful to peers, by giving advice (interview 3) or felt seen as a significant person by the caregiver (interview 6).

Nascent connecting to oneself. In contact with oneself, respondents indicated *growth in the relationship to oneself*. They gained more insight into oneself (interview 2, 7, 9 & 10), e.g., about the impact of attachment difficulties or traumatic experiences on their current situation of wanting to die, they got more inner peace (interview 9), accepted their inner vulnerability (interview 10) or had a greater capacity to allow assistance in their search for life and death (interview 10).

Nascent connecting to life. Several participants mentioned the experience of *allowing hope or meaning* in their life, sometimes in terms of experiencing new possibilities (interview 2, 9 & 10), feeling significance or a sense of belonging (interview 3, 6 & 9).

> The hospitality in the Reakiro House and feeling a bit at home here has been very important. … Even if my volunteering at the house is limited to just running errands and doing a wash-up, that is very valuable to me. It gives me a sense of belonging. - Interview 6

Some participants described the presence of hope or alternation of hope and despair (interview 6, 7 & 9). Meaning was derived from treatment possibilities (interview 2, 9), feeling more able to bear one's difficulties (interview 10), hope for engagement in society (interview 6, 10), or even from the donation of one's body to science (interview 3). Participants expressed the experience of *engaging in life*. They tried to sustain daily life (interview 1 and 6), engaging in contacts with other people as a way of investing in life (interview 1) or wanted to invest in therapeutic treatment (interview 2 & 9). One participant expressed that the availability of the option of euthanasia helped to engage in life (interview 7). One respondent expressed that a therapeutic context, in which it was permitted to talk about the death wish, helped to *experience the right to exist* (interview 10).

> The idea that my death wish is allowed to be there, makes it possible to deal with it. … Meanwhile, I allow myself to have a death wish. As a result, I came to believe that I am not all bad as a human being because I carry a death wish since childhood. – Interview 10

The results of the study provided the foundation for the development of a hypothetical model (Figure 1). The research demonstrates that the relationship between interviewees and the death wish is influenced by their relationship to life, and vice versa. The long-term death wish, mostly early onset and perceived as a salvation from suffering, has different expressions and can range from a very compelling wish to an ambivalent attitude to a temporary abandonment of the death wish. The study also revealed that, in addition to the death wish, some respondents expressed fear of death, while others displayed indifference. Fear of suicide was identified as a factor contributing to the contemplation of euthanasia by some respondents. The analysis indicated that the process

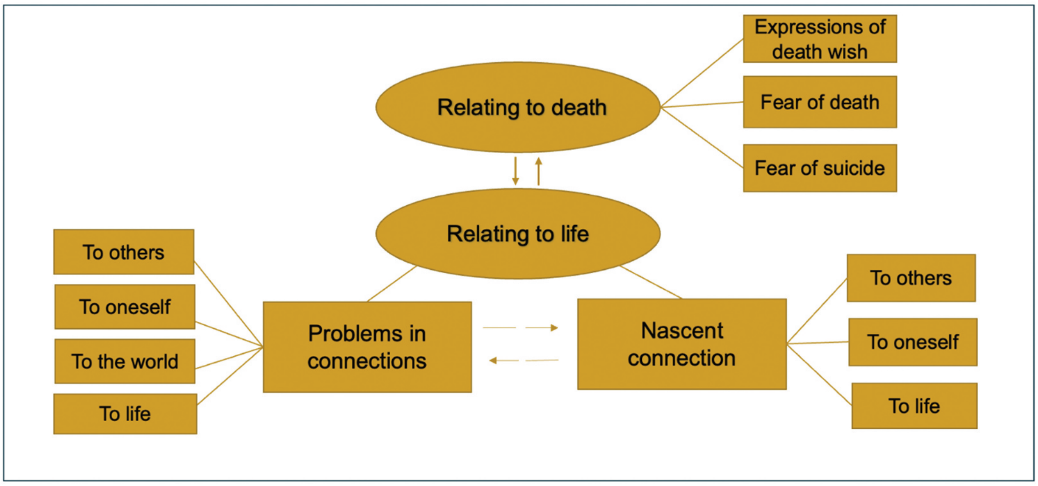

Figure 1. Integration of research findings in a hypothetical model.

of grappling with the death wish is accompanied by a concomitant struggle with life, which is perceived as unbearable. This struggle is characterized by difficulties in establishing connections with various domains, including relationships with others, with oneself, with the world, and with life itself. Notwithstanding the death wish, attempts are made to establish connections, and on occasion, nascent connections emerge with others, with oneself and with life itself.

Discussion

The findings of this study are intended to facilitate a more profound comprehension in how individuals with DWUPS experience their death wish and the concomitant life challenges. The study emphasizes some important clinical implications with regard to the approach adopted in relation to individuals with DWUPS.

Suicide versus euthanasia

The care for relatives was prominent in the study: giving relatives the opportunity to say goodbye and desiring to shield their loved ones from the psychological distress associated with suicidal behaviour was an important factor in the consideration of euthanasia for most interviewees. This highlights the importance of involving relatives in counselling people with a death wish and, where appropriate, to foster contact. This may lead to new opportunities for contact or sharing of unbearable pain and the desire to die.

Some participants preferred dying by euthanasia but considered suicide in case of not being eligible for euthanasia. The fear of pain, fear of failure when attempting to die by suicide played a role in this. The findings reported by Nicolini et al. (2022), who observed that the association between suicide and euthanasia is predominantly associated with capability, are in line with our results. These findings contradict the stance of Creighton et al. (2017), which distinguished between suicide and euthanasia by characterizing suicide as an impulsive and violent action, and euthanasia as planned and well-considered. At the same time, participants express feeling surrendered to the medical professional in the process of euthanasia. Moureau et al. (2023) emphasize the significance of autonomy in the decision-making process capacity of individuals with severe and persistent mental illness.

Relating to life and death

Figure 1 shows that in our study, the death wish is interconnected to problems in connecting to others, to oneself, to the world and to life. At the same time, respondents report how they attempt to establish connections with others, with themselves and with life.

Nascent connecting to others

Interviewees emphasized the pivotal role of caregivers' presence in fostering connections. Authentic encounter, where the caregiver acknowledged deep pain and suffering, was vital for initiating relational depth. Participants described a lack of meaningful connections with others and difficulties in allowing others, often leading to self-isolation and a sense of solitude. These challenges frequently stemmed from early attachment issues, loss of secure relationships, or a lingering sense of abandonment. The findings of previous research on suicide (Hill & Pettit, 2013; Joiner, 2005; Klonsky & May, 2015) and psychiatric euthanasia (Ricou & Wainwright, 2019), describing experienced disruptions in the connection of these individuals with others, are in line with our study.

Sharing the death wish with another person was found to be therapeutic, occasionally leading to repaired connections. Even when the death wish felt urgent, participants expressed a need to voice their concerns. Exploring the multifaceted nature of the death wish, encompassing its fluctuations and dualities, including its associated fears of annihilation or identity loss, provided opportunities for building new connections. The death wish itself can create a gap between person with DWUPS and their loved ones: they wish to shield their loved ones from the distress of impending loss and at the same time, they are reluctant to comply with the pressure exerted by their loved ones to prolong their own life. Schulz-Quach (2018) refers to the existential gap that emerges between an imminently dying existence and those who accompany this process as a witness.

The majority of participants reported non-aligned care, asserting that their autonomy was compromised during euthanasia procedures. Furthermore, they noted that the care provided often failed to address their complex needs and was excessively focused on recovery. This ultimately results in a failure to acknowledge the individual's death wish. The findings of Verhofstadt et al. (2021), showing that persons with a request for psychiatric euthanasia feel worthless or worn out because of experiencing health care deficiencies, are consistent with our observations.

The significance of providing companionship during challenging experiences has the potential to develop relational depth, trust and bonding (Cooper, 2015; Moonen et al., 2016). The caregiver's attitude of presence can facilitate the individual's ability to connect with and make sense of their extremely difficult experiences. Moreover, the process of fostering connections not only alleviates feelings of alienation and existential frustration (Glaw et al., 2017) but also creates space for individuals to explore ambivalence between life and death, recognizing both positive and negative aspects, including pleasure and pain, security and danger, vitality and vulnerability. In contrast to a focus on change, this approach can help to confront unrelieved suffering and the wish to die, while maintaining an openness to new possibilities. Greening (1992) described the importance of being able to connect to an ambivalent stance towards life and death and creating a holding space where the unsolvable dynamic tension between both opposite attracting poles are met. This process contributes to a greater sense of existential maturity and freedom. The existential approach to palliative care as described by Moureau et al. (2023), which emphasizes responsibility and dignity in individuals requiring presence to find hope or inner peace, is in line with our findings. The most significant route to growth and transformation is not merely discussing the life difficulties, but rather to be with the client's experiences pertaining to those life difficulties and to make them present in the session itself (Vanhooren, 2023). This does not necessarily imply the abandonment of the death wish; as demonstrated by the results of the study, it may instead lead to another relating to the death wish, characterized by increased levels of shared experience and decreased levels of isolation.

Nascent connecting to oneself

It is of the utmost importance to emphasize the acceptance of suffering and vulnerability, rather than focusing on the recovery process as a way to change. The latter approach may potentially result in increased pressure and a sense of failure. Trachsel et al. (2016) plead for a palliative psychiatry which focuses on mental health and therapeutic alliance, rather than aggressive care within current paradigms. This approach has the potential to facilitate a more profound comprehension of one's own death wish, thereby enabling individuals to adopt a more serene perspective on life and death. Consequently, this could assist in making authentic choices regarding life and death.

Despite the confrontation with persistent or even worsening unbearable suffering and the accompanying death wish, our interviewees experience growth, in getting insight in the impact of trauma and attachment issues on their death wish and on their vulnerability in general, in finding more inner peace, accepting one's vulnerability, or allowing assistance. Suffering is omnipresent, physically, and mentally, related to unprocessed traumatic- or loss experiences, such as neglect, abandonment, lack of security or acceptance, often originated in early childhood. This suffering is related to the death wish, which is perceived by most interviewees as a salvation from suffering. They feel unable to cope with grief- or traumatic experiences, which has a major impact in daily functioning. In insecurely attached individuals, grief processes can be complicated and need a nuanced and tailored approach (Kosminsky & Jordan, 2016).

Nascent connecting to the world

In our study, we could not find fostering connection to the world. Other research shows that stigmatization is often worse than the condition itself (Thornicroft et al., 2022). It is possible that individuals with DWUPS require a greater amount of time and energy in order to establish a connection with their caregivers. The provision of a supportive environment that facilitates the gradual establishment of connections, tailored to an individual's capabilities, can serve as a foundational element in the development of subsequent relationships with other members of society. Working with patient-experts can contribute to feeling recognized and less alienated. The establishment of initiatives aimed at facilitating the social integration of people with DWUPS, such as working with buddies, has the potential to facilitate connections with the world.

Nascent connecting to life

Interviewees describe their efforts to establish a sense of connection with life through the cultivation of hope or new possibilities, engagement in novel experiences that impart a sense of personal significance, or a sense of belonging. Early experiences of being ignored or rejected, as well as devastating experiences of abuse or neglect generally develop a core sense of self as defective, not mattering, worthless, and unlovable (Dearing & Tangney, 2011). Respondents describe lacking vitality, feeling exhausted mentally or physically, experiencing no joy, no hope or sense of significance, feeling even groundless or unable to experience the right to exist. Greenberg (2024) describes how persons who suffer from feelings of core shame may be too vulnerable to feel or express joy out of fear that any good feelings could be taken away. Caregivers can help individuals with DWUPS access joy and pride in self and to open up to others. A return to the experience of pleasure may also facilitate a broader engagement with life itself.

Research of Lew et al. (2020) demonstrates how both presence of meaning is a protective factor in suicidal persons and a mediator between hopelessness and suicidal behaviour. At the same time, a study of Davidson et al. (2009) points us to the dual meaning of hope: while it is protective towards experiences of burdensomeness and thwarted belongingness, it is also related to a higher capability to suicide, possibly related to more risk taking when hope is reinforced.

So, it is important to balance hope and meaning with achievable goals and steps in life. Helping persons with DWUPS to allow hope and meaning in a careful way, to alternate between hope and despair, meaning and meaninglessness, to develop the ability to hold and consider contradictory ideas in one's mind at the same time contribute to more openness to meaning, to curiosity and receptivity. Furthermore, creating a frame of reference about human suffering and life that makes sense to the person and the care provider can be helpful to enhance wellbeing, willingness to engage in therapeutic work and ultimately in creating meaning (Glaw et al., 2017).

To help individuals with DWUPS to relate to the existential layer of their inner experiences, therapists need to develop the courage and the capacity to sense and resonate with the person's existential concerns, to symbolize and to communicate this resonance to the person (Vanhooren, 2022). This can support the individual in engaging in a meaningful exploration of the inner self, of ambivalences and the implicit intricacy of inner experiences, from an attitude of curiosity about the unknown aspects of the inner world (Gendlin, 1996; Rogers, 1961).

Strengths and limitations

A significant strength of this study is its articulation of the experiences of persons with a long-standing death wish related to unbearable psychiatric and existential suffering. Persons with severe mental illness frequently face exclusion from such discourses due to their perceived vulnerability and perceived lack of capacity.

In this study, confirmation bias was rigorously monitored through a systematic re-evaluation of the extant body of knowledge, based on the person's responses. The combination of an experienced researcher with an open-minded graduate student helped to ensure that bias was avoided as much as possible.

To ensure the impartiality of the research and to minimize social desirability bias, the interviewer was not involved in the counselling or the person's euthanasia procedure. Concurrently, the experience of therapeutic work with individuals who were highly vulnerable facilitated attunement to the persons, which resulted in data of considerable richness and complexity.

Regarding the limitations, the interviewer indicated that certain difficulties were encountered. One of the scheduled interviews was cancelled due to the person experiencing a relapse in substance abuse and severe dissociative symptoms. There were differences in the degree of verbality of the respondents, which resulted in slightly less extensive information for some candidates. One of the respondents demonstrated difficulty in maintaining attention, necessitating a more structured approach to conducting the interview.

The results of this study cannot be generalized to the entire population of people with DWUPS, as only ten interviews were planned and conducted. In addition, the study population only included people who had been receiving existential care at Reakiro for one to one and a half years. Although the same categories were identified in the final interviews as in the earlier ones, it cannot be concluded with certainty that the data are fully saturated. Nevertheless, the analysis of the interview data provides important insights into the lived experiences of people with DWUPS. Further research is needed to test the hypotheses formed and to formulate further recommendations for clinical practice.

All participants were Belgian persons and have the option of requesting psychiatric euthanasia. Possibly, persons residing in countries where psychiatric euthanasia is not an option could provide further insights into their experiences of life and death.

Conclusions

The present study sought to elucidate the lived experiences of life and death of individuals with a long-lasting death wish. This comprehension can assist clinicians in fostering connection with these vulnerable persons. The model of palliative psychiatric care (Trachsel et al., 2016) can serve to supplement recovery-oriented care, particularly considering the constraints associated with treatment options for persons with complex care needs. This approach allows for the acknowledgement of unbearable suffering while maintaining an openness to possibilities. From an attitude of authentic presence, the caregiver can help individuals with DWUPS to make sense of their vulnerability and death wish. The process of understanding how traumatic experiences and severe attachment problems have led to a desire for death can facilitate a reduction in feelings of deep loneliness. A shift in emphasis towards existential care, initiated from a respectful interpersonal stance and informed by existential empathy (Vanhooren, 2022), has the potential to foster relational depth in the therapeutic relationship, transcending the gap between life and death. Encouraging connection between caregiver and the person with DWUPS is equally applicable to loved ones.

The provision of attuned care for individuals with DWUPS necessitates a careful fostering of hope, meaning and belonging. This approach facilitates navigation through tumultuous experiences, encompassing the oscillation between hope and despair, life and death, suffering and care, loneliness and connection. This does not necessarily lead to an abandonment of the death wish, but rather to an alternative way to relate to it, as a shared experience instead of an isolated one.

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