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Request for euthanasia by a psychiatric patient with undetected intellectual disability

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SUMMARY

In the Netherlands, euthanasia or assisted suicide (EAS) in psychiatric disorders is legal in certain circumstances. Guidelines recommend a second opinion to independently check diagnosis and treatment resistance. A 68-year-old patient, diagnosed with bipolar I disorder, with a request for euthanasia because of tiredness, repeated falls and racing thoughts was seen for such a second opinion. Persisting in her wish, her reluctant family and psychiatrist became convinced of euthanasia. Our disagreement with the diagnosis of bipolar I disorder upset her, but she agreed with discontinuation of psychotropic drugs. Her mobility and tiredness improved, whereafter her request for euthanasia evolved into a death wish due to completed life. Intellectual disability and an attention deficit hyperactivity disorder could explain her struggle in life. This case report shows that extending the procedure regarding EAS with an independent psychiatric evaluation is important. For our patient, this second opinion supported her to find meaning in life.

BACKGROUND

Euthanasia or assisted suicide (EAS) is increasingly accepted as a last resort for patients with unbearable suffering due to a terminal somatic illness with limited life expectancy. For patients who are not terminally ill, like those suffering from a treatment-resistant psychiatric disorder or early-stage dementia, EAS is much more controversial and has only been legalised in a few countries, including the Netherlands.[1] In the Netherlands, the incidence of EAS in psychiatric patients has increased over the past two decades, but actual numbers remain rather low,[2] despite high prevalence of psychiatric disorders and dementia and dreadful suffering of these patients. This could be because assessment of the due care criteria (see box 1) is more complex in patients with severe mental illness, especially the assessment of mental capacity, the judgement whether the wish to die could be a symptom of the psychiatric disorder, and prognostic uncertainty.[3] Furthermore, EAS in patients suffering from non-terminal illnesses is much more controversial and highly debated in politics, media and professional societies.[4 5] On the other hand, considering the poor prognosis of psychiatric disorders and their impact on quality of life in some patients, critics state that psychiatrists should take their responsibility to enable EAS in psychiatric patients who meet the due care criteria. To perform EAS, a physician needs confirmation of the due care criteria by one independent physician by law. In case of suffering due to a psychiatric disorder or dementia, clinical guidelines also recommend an additional second opinion by a psychiatrist to check the patient's competence, and to re-evaluate the psychiatric diagnosis and potential treatment avenues.[6] Even when the treating physician consider the patient's symptoms refractory, a second opinion may shed new light on the patients' diagnosis and/or treatment possibilities, which may even result in complete recovery.[7]

An EAS request by an older patient with a severe mental illness is further complicated when cognitive impairment is thought to interfere with the request for EAS, like intellectual disability or early dementia. Among patients with severe mental illness, a diagnosis of dementia can be very challenging,[8] and intellectual disability often remains undetected.[9] Dementia as well as intellectual disability may also be misdiagnosed as a severe mental illness. This latter misdiagnosis is not uncommon as intellectual disability itself is associated with an increased risk of behavioural disturbances and complicates their treatment.[10 11] In this case report, we present a case of a 68-year-old woman with undetected intellectual disability who requested euthanasia based on a misdiagnosis of bipolar disorder.

CASE PRESENTATION

A 68-year-old woman, diagnosed with bipolar I disorder in her early 20s, presented to our outpatient clinic for geriatric psychiatry for a second opinion to proceed in her request for euthanasia. She reported problem of unbearable suffering due to extreme tiredness that has gradually developed over the past years and 'racing thoughts' in her head as long as she remembered. She was eager to tell us about her life history. She was the third child in a poor family with 11 children. In school she experienced problems with reading and writing. She left school prematurely at age 14 and started working as a stock clerk in a warehouse, then as an auxiliary nurse in a hospital. At 18 years, she impulsively moved to the other side of the country. At age 25 she became 'burnt out', which led to her first admission to a mental health hospital. Despite many periods of inpatient treatment over the next years, her husband lovingly cared for her till he unexpectedly died when she was aged 39. She was subsequently admitted for years at a long-stay ward in a mental hospital in her hometown in Northern Netherlands. Temporary emotional states or daily life hassles repeatedly resulted in augmentation of

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Box 1

Statutory due care criteria

Under section 2 (1) of the Act, physicians who carry out an EAS request must:

1. Be satisfied that the patient's request is voluntary and well considered;
2. Be satisfied that the patient's suffering is unbearable, with no prospect of improvement;
3. Have informed the patient about his situation and prognosis;
4. Have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient's situation;
5. Have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out in (1) to (4) have been fulfilled;
6. Have exercised due medical care and attention in terminating the patient's life or in assisting in his suicide.

psychotropic drugs as well as an advice by a university clinic (but never given) electroshock therapy to treat her 'rapid-cycling pattern'. After years of lithium usage, discontinuation due to renal failure 10 years ago remarkably did not result in any changes in her mental status. When her mood remained relatively stable for 20 years, she started living independently with psychiatric homecare.

Psychiatric examination did not reveal any signs of mood disturbances or psychotic features. The reported mood swings did not meet criteria for a depressive or manic episode. Higher cognitive deficits attracted most attention in psychiatric examination. She was not able to tell her biography chronologically, even with support of the examinator. She was easily distracted by her own thoughts and could not focus on the conversation sufficiently (without impaired consciousness). She mentioned that she was very tired and unable to self-care at home. Physical tiredness resulted in repeated falls at home. Racing thoughts, which had been present even in youth, resulted in mental fatigue.

After her brother died, she longed for the same peace that her laid-out brother displayed at his funeral. Her longing for peace was reinforced inadvertently by home care professionals, who comforted her by saying that her brother had finally found rest and peace. When she heard about the possibility of euthanasia for mental suffering, her request for EAS was born.

Her niece and other family members were initially shocked by her request for EAS. Nonetheless, they gradually became convinced this was the best solution.

DIFFERENTIAL DIAGNOSIS

Despite no evidence for the presence of a bipolar disorder, all psychiatric correspondence repeatedly stated that she suffered from a bipolar I disorder. The original correspondence in which the diagnostic process was described, however, was not available anymore. Moreover, while many psychiatrists had taken the diagnosis of bipolar I disorder for granted in the past, none of them had substantiated the diagnosis of bipolar I disorder in their correspondence. The lack of confirmation of any manic episode made us suspicious.

Her treating psychiatrist, who had known her for 20 years, as well as her primary care physician, both told us that they had never seen her in a depressed or manic state. Nonetheless, the number and dosages of psychotropic drugs were consistently increased as she often asked for more drugs when feeling physical and/or emotional pain, probably due to limited coping skills. Her current tiredness, therefore, could easily be explained by inappropriate drug use built up over the years, that is, olanzapine 5 mg, carbamazepine 400 mg, pregabalin 75 mg, oxazepam 20 mg, fentanyl patches of 75 µg, oxycodone 30 mg; in addition to several drugs for her physical condition.

Based on her intellectual performance, biographic reconstruction, and problems of racing thoughts, we considered intellectual disability, potentially with a comorbid developmental disorder, most likely either attention deficit hyperactivity disorder (ADHD) or autism spectrum disorder. Nonetheless, a bipolar I disorder as well as an incipient neurodegenerative disorder could not be excluded yet.

INITIAL CONCLUSION SECOND OPINION

Doubting her primary diagnosis, we stated that the due care criteria for performing EAS were not met. We advised admission to a ward for geriatric psychiatry for discontinuation of as many psychotropic drugs as possible, detailed psychiatric examination, and neuropsychological testing.

OUTCOME AND FOLLOW-UP

Although the patient was disappointed that her request for EAS could not be granted yet, she agreed to inpatient drug withdrawal, observation and neuropsychological testing. Over a period of 6 weeks, we were able to discontinue all psychotropic and sedating drugs without any mental or physical problems. Furthermore, we initiated and optimised treatment for somatic disorders (type II diabetes, COPD). Her physical functioning strongly improved, and she was able to grasp something from the ground without falling and to walk without aids. Neuropsychological testing demonstrated intellectual disability (with a verbal IQ of 74 and performal IQ of 45) based on Wechsler Adult Intelligent Scale and no indication for cognitive decline.

Despite these developments, she still asked for EAS to find peace. Her main problem was her racing thoughts, which were considered residual symptoms of ADHD. While these symptoms responded well to treatment with amphetamine 5 mg two times per day, treatment had to be discontinued due to high blood pressure.

Nonetheless, we were able to discuss other possibilities for finding peace and rest within the framework of life review.[12] She was willing to contemplate that it would be nice if she would give others a happy feeling by letting them care for her. Although she remained ambivalent regarding her request for EAS, she gratefully took the opportunity to be supported in her search for peace in life for the next 12 months.

DISCUSSION

Unfortunately, unrecognised mild intellectual disability, as our patient had struggled with throughout her life, is not an exception.[9] Rigid and simplistic thinking due to intellectual disability, beside her persuasion of treatment resistance of the 'bipolar 1 disorder', had led to a persistent request for EAS. This persistent request was understood by her loving-caring family and judged by her treating physicians as acceptable as due care criteria were met on the basis that the patient was unbearably suffering from a treatment-resistant bipolar 1 disorder. Nonetheless, the diagnosis of bipolar 1 disorder was refuted by our second opinion. As a result, our patient did not meet the due care criterium 'suffering is unbearable without prospect of improvement' (as well as the other criteria) anymore. Her ongoing suffering was in fact based on iatrogenic damage (side-effects of mood stabilisers

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and sedating drugs) as well as a missed diagnosis of intellectual disability and of ADHD in later life (racing thoughts).

This conclusion turned her identity upside down, as she was completely one with the diagnosis of bipolar disorder. Remarkably, being diagnosed with intellectual disability and ADHD was not a big issue for her. She was happy that the symptoms that made her life unbearable could be managed, but her death wish initially remained. In other words, her request for EAS based on a lack of prospect on improvement due to therapy resistant bipolar I disorder, converted into a death wish on completed life, potentially as a coping mechanism for her struggles in daily life or her lack of meaning in life. Her life felt completed, as she could not image that she might be able to care for others in some way. In the end, however, rediagnosis and a fitting supportive environment made it possible for her to reconstruct her biography, understand her struggle in life and most importantly, to be proud again of what she had meant for others.

In the literature, euthanasia in patients with intellectual disability generally focusses on the legal and ethical considerations of performing euthanasia on severely handicapped young persons. These (very) young persons are generally considered incompetent to decide on their own life, which is often judged as incompatible with human dignity.[13] Based on the online case summaries of the regional review committee (Regionale Toetsingscommissie Euthanasie), a case series including six adult cases with intellectual impairment who were granted EAS in the Netherlands has been published.[12] These cases had mostly mild intellectual disability in addition to mental–physical multimorbidity. Nonetheless, physicians had profound difficulty in assessing capacity, since discrepant findings of physicians as well as refusal of physician to assess capacity were reported. Moreover, information about the due care criteria informing the patient about his/her situation and prospect was limited, and when given, explicitly stated 'on the level of patient'.[14] On the other hand, professionals generally agreed regarding the due criteria of unbearable suffering as well as having reasonable alternative treatment options. Since unbearable suffering is subjective and should be seen in light of the patients' own history, we cannot exclude that accepting this due care criteria partly reflects a cultural view on human life of Western professionals. Nonetheless, our patient, although with some ambivalence, accepted treatment based on life review in a warm supportive environment to help her find meaning in life again. If she had not accepted, or this is not effective after 1 year, this case will pose an ethical question 'Can we, as professionals, have delayed proper diagnostics that much, that we should now grant EAS due to iatrogenic damage and the fact that she appears to be too rigid to change her mind or do we have to decline her EAS request despite her consistent death wish?' According to the Dutch law, her remaining death wish would be classified as completed life, not meeting the due care criteria for euthanasia. In the Netherlands, legalisation of assisted suicide for completed life is a timely topic as a concept law has been sent to the lower House of Parliament in July 2020.

Patient's perspective

As her closest family member, I have always been unsure whether she would persist in her wish for euthanasia. She struggles with discussing how she feels and never really wants to go 'deep', so I could never really determine how serious her wish was. Her emotions always show as pain and lead her to ask for a pill. She can be very impulsive and headstrong, and she tends to get what she wants, which I am now beginning to place in the context of her diagnosis of ADHD and intellectual disability. I really hope that she will be able to pick up her life and find meaning again in the upcoming months. I am curious what her future will bring now.

Learning points

- Never take a persistent death wish for granted, not even in severe mental illness existing for >40 years and or when patient, loving-caring family and treating psychiatrist have all become convinced that euthanasia would be justified.
- Always search for the meaning behind a request for euthanasia—what does the patient really want—and accept simple wording in case cognitive performance is limited for whatever reason.
- Always consider intellectual disability as well as cognitive decline or acquired brain damage in case of severe mental illness and/or psychotropic polypharmacy.

Contributors The initial second opinion was performed by ROV and the subsequent inpatient diagnostic proces by AvdP-M. The initial draft of the case report was written by OS under close supervision of RM. All authors have commented on previous versions of the manuscript. The final manuscript was approved by all coauthors as well as the patient herself and her caring niece.

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