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CASE REPORT

Experiences with euthanasia requests of persons with SCI in Belgium

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Abstract

Introduction Living with SCI remains a challenge and some patients fear or are faced with an inability to master this challenge sufficiently to regain a satisfactory quality of life. The suicide rate within the population with SCI is elevated compared with the general population. Especially now that life expectancy of persons with SCI and age at onset of SCI are increasing, caregivers of persons with SCI can be confronted with requests for end-of-life care or even assistance in dying. Euthanasia remains worldwide a controversial topic, but has rarely been discussed in the context of SCI.

Case presentation The medical history and the results of in-depth interviews with three persons with tetraplegia, between 36 and 88 years old, with a profound and repeated request for euthanasia testify of the importance of an open-minded dialogue concerning end-of-life questions, in which all options can be considered, and limits of patients' capacities and best care results are acknowledged.

Conclusion These cases suggest that a well-regulated strictly controlled legal framework, handled with prudence and proficiency, can be an added value to the care for persons with SCI.

Introduction

As a result of care improvements in the acute and post-acute phase after spinal cord injury (SCI), research attention has shifted from improving survival rates after SCI to supporting living with SCI and its different challenging aspects. However, research on the aspect of dying with SCI and care for end-of-life requests of persons with SCI is limited. While life expectancy of the population with SCI and mean age at onset of SCI increase [1], the importance of end-of-life care is growing as general life satisfaction decreases with growing age [2] and functional capacities decline and the vulnerability increases [3]. The high suicide rates in the population with SCI [4] illustrate a need for specific care for SCI patients who do not obtain a sufficient quality of life (QOL) and desire to decease.

Euthanasia is a controversial topic worldwide [5]. Belgium and the Netherlands were the first countries in the world to implement a legal framework to permit euthanasia in well-defined circumstances. The Belgian legal framework was implemented in 2002 and permits euthanasia when the request is well-considered, voluntary, sustainable in time and repeated. The patient must be well-informed, legally capable and in a condition of constant unbearable physical or mental suffering which cannot be alleviated (Fig. 1). The request must be well-documented and reviewed by at least 2 or 3 physicians. In absence of terminal disease, a one month interval between the request and the euthanasia procedure must be respected [6, 7]. A survey on the experience of Dutch and Belgian SCI physical and rehabilitation medicine (PRM) physicians showed general satisfaction with the legal framework [8]. Research on end-of-life care after SCI is limited. However, the importance of the topic is growing as life expectancy after SCI and age of SCI onset are increasing. Three cases are presented to illustrate how this regulation is appreciated by persons with SCI and how it influenced their rehabilitation processes.

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<u>Euthanasia</u>: **intentionally terminating a person's life by someone else than the person concerned, at the latter's request.**
The physician who performs euthanasia commits no criminal offence when he/she ensures that he/she acts in accordance with **criteria of due care**

<u>Criteria of due care:</u>

A. <u>Patient:</u>
- Age of majority or emancipated minor OR terminally ill minor competent to judge with consent of legal representative;
- **Legally competent** and **conscious** at moment of request;
- Request is **voluntary, well-considered and repeated, without external pressure;**
- **Medically futile condition of constant unbearable physical or mental suffering;** resulting from a serious and incurable disorder caused by illness or accident; **suffering that cannot be alleviated**;

B. <u>Request:</u>
- **Written** request obligatory (document dated and signed by person him/herself);
- If not capable to write:
  - document may be drawn up by adult unprejudiced person designated by the patient, in the presence of physician whose name is mentioned on the document
  - document indicates that patient is incapable of writing and reasons why;
- All requests and all other actions by the physician and their results incl. reports of the consulted physicians(s) are regularly noted and **kept in the medical record;**

C. <u>Information and consultation:</u>
- Patient is **well informed** about his/her situation, life expectancy and prognosis;
- The request and possible therapeutic and palliative options and its consequences are discussed;
- The physician needs to ascertain that there is **no reasonable alternative and the request is durable and voluntary** of nature during several conversations over reasonable period of time (taking the progress of the condition into account);
- The physician needs to **consult another independent competent physician** and inform him/her about serious and incurable character of disorder and reason for consultation;
- The consulted physician reviews medical record, examines patient and must ascertain constant and unbearable physical or mental suffering that cannot be alleviated. He must report his/her findings;
- If patient is a minor: the physician must likewise in addition consult a psychiatrist or psychologist with expertise on children or youth to determine if the minor is competent to judge
- In case the patient is treated by a team of nurses, the physician must consult this team or members of this team;
- If patient wishes, the physician must discuss the request with significant others;

D. <u>If patient is not expected to die in near future:</u>
- The physician needs to **consult a second independent physician** (psychiatrist or specialist in the disorder in question) and must inform him/her about reason for consultation;
- The second consulted physician: reviews medical record, examines patient, ascertains about the constant and unbearable physical or mental suffering that cannot be alleviated + about the well-considered and repeated request. He/she must report his/her findings;
- Allow **at least one month between** the patient's written **request and** the act of **euthanasia;**

E. <u>Control:</u>
- The physician who performed euthanasia must fill in **a registration form, addressed to the Federal Control and Evaluation Commission** and deliver it within 4 working days;
- This form includes: confidential open part (with e.g. demographic data of the patient and his/her death, characteristics of the pathology and the unbearable suffering which cannot be alleviated, data of the consultation(s) with an independent competent physician, the request, the followed procedure, method of euthanasia) and an anonymous part (incl. names of physicians involved)
- **Commission studies the open part of the document** and determines whether euthanasia was performed in accordance with the conditions and the legal procedure
- In cases of doubt: anonymous part is opened and physician can be asked to explain or deliver parts of medical record
- **If conditions are not fulfilled: case is turned over to public prosecutor**

Fig. 1 Belgian legal framework for euthanasia

Case presentation

In the first case, we present a man aged 88 years with traumatic tetraplegia C4 AIS D (central cord syndrome). Before the injury, he was a busy healthy elderly person who liked to work in his garden. A few days after the fall, he expressed the wish to stop living. It was primarily the experienced dependency upon others that broke his spirit. However, his muscle strength increased and he found the courage to start a rehabilitation process. Two months after the injury he encountered increasing pain and spasticity with functional decline. Again, he expressed the wish to end his life and requested euthanasia explicitly. The PRM physician explained the legal framework and provided alternative options to alleviate his suffering. New rehabilitation goals were set and the palliative care team was consulted to optimise pharmacological pain treatment and comfort. However, his pain further increased and therapy-resistant spasticity became prominent. Multiple strategies were worked out to minimise discomfort. Nevertheless, the more was tried, the more persistent his wish to die became. From his perspective, the symptoms were very bothersome but irrelevant. It was life itself which made him suffer unbearably. Although he acknowledged that some beautiful

and enjoyable moments were still ahead, he could not imagine enjoying these moments, without being able to be independent in self-care. During multiple exchanges with the psychologist, the psychiatrist, a nurse, a priest and the PRM physician, the euthanasia request was explored and evaluated. According to these experts, his judgement and ability to take decisions was not compromised by external pressure, mood disorder or cognitive impairments. He was aware of the implications of his request, including the impact on his family. No doubt entered his mind and he stated the euthanasia question increasingly in an irrefutable way. Advance directives were designed and signed. The euthanasia request was documented, in accordance with the legal conditions. The ethical committee of the institution was consulted, and an ad hoc committee was organised. The legal terms were checked, the ethical justifiability and the impact on the social network were estimated. After a positive advice of the ethical board, the euthanasia was carefully prepared with the patient, his family and his rehabilitation team. The patient expressed that granting his request helped him to find inner peace. During an in-depth interview in the rehabilitation centre, shortly before the planned date of euthanasia, he expressed his gratitude for the life he had lived and for the life he would not have to live. He said goodbye, without resentment. The euthanasia was carried out by the treating PRM physician in the presence of his wife and children in a separate studio, adjacent to the rehabilitation centre, four months after injury. Almost 1 year after his death, the psychologist and the PRM physician had a meeting with his family. All of them declared to be grateful for the way their relative was honoured in his wish and valued as a person. Beside grief, they expressed gratitude for the great care and the dignified death.

The second case report describes a 61-year-old man with traumatic tetraplegia C4 AIS B. Two days after the injury, he requested euthanasia firmly and repeatedly. The treating physician explored this request. Information on euthanasia and the legal criteria, as well as information concerning SCI and rehabilitation was given. After some negotiation, the patient agreed to re-evaluate his request after 6 months of therapy. During the rehabilitation period, a subtle increase of strength in his right arm enabled him to reach his mouth with his hand and drive an electrical wheelchair with joystick. The euthanasia request was not repeated when he left the rehabilitation centre after 1 year. Eighteen months after injury, he was interviewed in his home, where he lived alone with assistance on demand. He enjoyed life at that moment and had no current wish for euthanasia. However he was aware of his vulnerability and not prepared to make any more concessions regarding his independency. The courage needed to pursue life was strengthened by the security that he would be supported the moment he could not bear it anymore. He was convinced that he would search for ways to commit suicide if the legal option for euthanasia would not exist, and would need to carry out this plan prematurely, before his strength would have declined too much. Empowered by the assurance of this legal option, he was able to enjoy life until multiple major SCI complications started to succeed one another 4 years after injury. He started the euthanasia procedure but stopped it himself before the planned date. When his general condition continued to decline 2 weeks after he stopped the euthanasia procedure, the patient, his general practitioner, his family and the team of closest caregivers decided jointly to start palliative sedation. He died 36 h later, surrounded by his caregivers without pain.

The third case involves a 36-year-old man, with traumatic tetraplegia C2 ASIA A since the age of 16. He was dependent for all care and invasively ventilated. Verbal communication occurred through speech cannula. He managed to drive an electric wheelchair with head control and operated his computer. His home environment, where he lived with his parents, was adequately adapted to his needs. At the age of 31, he attempted suicide. During therapy after this event, advance directives were documented according to his wishes. Mostly out of concern about the wellbeing of his parents, he decided to continue his life. However, the wish to end his life became increasingly intrusive. At the age of 36, he discussed his request for euthanasia with his general practitioner, his parents and his treating PRM physician. He expressed unbearable suffering, but it was difficult for him to specify the causes. Most importantly he expressed eternal regret of not being able to move his body, resulting in being totally dependent on others. It also became increasingly difficult to deal with the continuous pain. The care he received was perceived as optimal. Alterations of care could not have any meaningful positive influence on his QOL. For years, he was registered with the wish to donate his organs after his death. This possibility meant a lot to him because it would enable him to help others, after all the care he received. The patient was evaluated by a psychiatrist, who stated that the patient had an unclouded mind, no treatable mental health condition and the request was well-considered. Respecting the values, the strength and the limits of the patient, his family and caregivers all accepted that euthanasia was the only adequate option to alleviate his suffering. The ethical committee verified that the legal criteria were met and approved his wish for organ donation. Pre-organ donation examinations were performed as per protocol. Details of the procedure were organized in two meetings of the team of organ donation and the team that would provide euthanasia. The man was interviewed shortly before the euthanasia was planned. According to him, euthanasia was certainly the best possible care in his situation. He was convinced he would attempt another suicide if this legal possibility would

not exist. He perceived the multiple evaluations and the mandatory interval between the request and the procedure as unnecessary in his case, since he had carefully considered this request for many years. The euthanasia was performed as planned, in presence of his family in the hospital. After the patients passing, he was immediately transferred to the operating theatre, respecting the legal period of 5 min 'no touch' to grant his wish for non-heart beating organ donation. Except for the kidneys, all organs were successfully transplanted. One year later the PRM physician and psychologist met the parents. They were still mourning but respected and understood their son's decision. An anonymous thanking letter of the person who received the patient's lungs was handed to them.

Discussion

Euthanasia remains controversial. Ethical reasoning about end-of-life issues is challenging, and clinical case descriptions have proven their potential to illustrate experiences and reflections [9]. Three cases illustrate the value the Belgian legal framework for euthanasia adds to SCI care and the thorough and multidisciplinary approach, necessary for every euthanasia request.

The Belgian legal framework for euthanasia guarantees patients if suffering remains intolerable, despite best care and great effort, they will not be forced to live through it. During rehabilitation, persons are invited to address the challenges and determine the treatment goals. However, believes and fears could hamper their rehabilitation [10]. Besides getting information and advice concerning therapeutic options, it is important patients share their insecurities and are acknowledged in their fears [11]. Due to the many challenging aspects of living with SCI, some seem in need of a worst-case scenario-plan in case they and their caregivers could not regain a satisfactory QOL. The acknowledgement of this need allows the patient to get a grasp on his insecurities, have a stronger resilience [12] and to better focus on rehabilitation. The legal framework enables physicians to work out this plan. This was illustrated in the second case. The patient could only be motivated to consider rehabilitation and life afterwards after he was reassured that he would not have to settle for an unsatisfactory QOL. Caregivers all over the world provide and organise the best possible care to reduce the burden of living with SCI. However, this care has its limits. Some encounter, years after their injury, that life itself becomes a struggle and QOL decreases. As life expectancy after SCI is increasing, it seems possible that it supersedes the capability to cope with challenges of living with SCI. If the fight is futile and no effort can reduce the suffering, some ask to be redeemed and aided in doing so, as was illustrated in the third case. Suicide accounts for between 5.8 and 11% of deaths following SCI [4]. Those statistics do not reflect the tremendous consequences of unsuccessful attempts, nor the suffering of those who desire to end their lives but aren't able to commit suicide. The man in the third case committed a suicide attempt as he suffered unbearably despite of optimal treatment. After this attempt, advance directives were designed together with the patient. Previous research pointed out the importance of advance directives [13]. As age of SCI onset is increasing [1], more and more elderly patients will find their way to SCI care and need an adapted approach [14]. The profound end-of-life questions that could arise in this population are illustrated in the first case.

The first and third case show the multidisciplinary approach needed to explore a euthanasia request. Only if no other care option could have benefit and QOL remains insufficient, a euthanasia procedure can start. In the third case, a combination of euthanasia and organ donation was organised according to the explicit patient's wish. This combination always requires a thorough review by an ethical committee. No pressure whatsoever, can be put on a person to choose euthanasia. The euthanasia and organ donation procedure were performed by two strictly separate teams. The legal terms were met in the first and second case and are illustrated (Fig. 1). The Belgian legal framework was installed in 2002. It was revised in 2014 to include minors in terminal condition [6, 7]. In 2003, euthanasia was preformed 235 times (0.25% of all Belgian deaths). In 2015, the euthanasia incidence had increased to 1.8% of all Belgian deaths (2022 times) [15]. The vast majority concerned terminally ill patients. The number of procedures in 2015 regarding various non-terminal neurological diseases, was 52 [15]. A federal control and evaluation commission checks the legal criteria in every registered case. If there is doubt about the legality of the procedure the responsible physician can be asked for clarification and ultimately the case could be turned over to the public prosecutor. This happened only once since introduction of the legal framework. Further critical monitoring and research will be necessary to check if this transpires to be sufficient to control the application of the law. The legal framework does not include an evaluation by the control commission before execution of the euthanasia procedure. This offers great responsibility to involved physicians. The legal criteria offer them absolute requirements to be met, but they're not precise and could be interpreted. Whether or not a physician is willing to take the responsibility of a euthanasia request, should always be a personal and non-influenced decision, in agreement with own conscience and values. No caregiver can ever be forced to be part of a euthanasia procedure. In the University Hospitals Leuven the policy is to organise an ad hoc meeting of the ethical commission to evaluate euthanasia request of patients without terminal illness.

The Belgian legal framework enables the patient's wish for a dignified death to be granted on stringent conditions. The mentioned cases further illustrate that it facilitates an open-minded dialogue concerning end-of-life questions, in which all options can be considered, and limits of patient's capacities and best care results are acknowledged. This reassurance may help to focus on rehabilitation and deal with the daily consequences of SCI. A thorough and multidisciplinary evaluation of each individual euthanasia request remains a prerequisite but an ethically difficult task.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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