Whether and how can the doctor help the patient who asks for death?

To the Editor We have to acknowledge that a desire to die is nothing unusual in palliative care. According to Back et al[1] and Craig et al,[2] between 10% and 30% of physicians are confronted with a direct wish for physician-assisted suicide. From 200 patients with advanced tumor, about 45% had an intermittent wish towards hastened death, and in nearly 10%, this wish was strong and persistent.[3] This desire to die is not restricted to cancer patients. Wish towards hastened death and suicide is also not infrequent in patients, for instance, with a neurological disease. In the MND/ALS study, a suicidal ideation has been reported for up to 30% of patients; in the Netherlands, 22% of patients die by euthanasia. In Parkinson disease, a similar number of patients have suicidal ideation and death by suicide is 5 times higher than for normal controls. Also in multiple sclerosis, death by suicide accounts for about 15% of cases, and in the Netherlands, 6% of patients die by euthanasia.[4-13]

The political discussion often comes already to conclusions when it is stated that "the patient wants to die". Our clinical experience, however, shows that this is a very differentiated syndrome. How do suicidality and the wish towards hastened death overlap? Is depression the most common cause? And what about the responsibility if a patient wants to commit suicide versus asking physician to assist in his or her suicide? At our department, we have performed quite a few research projects in recent years on the wish towards hastened death.[14-17] We have validated the Schedule of Attitude toward Hasten Death (SAHD), we have looked for the connection between the wish towards hasten death and the will to live, we have asked professionals regarding their reaction towards patients asking for this, and, currently, we are establishing a training program for professionals.

Lessons from research The main lessons we have learned so far, however, are 3-fold:

1 Talk about this issue proactively.

2 Take a desire to die as a differentiated syndrome.

3 The wish towards hasten death and the will to live often coexist!

Talk about this issue proactively As has been known in psychiatry for a long time, asking patients with suicidal ideation about this issue does not make them more likely, actually, to commit suicide. However, this knowledge has not really spread into palliative care so far. Here professionals are still very frequently afraid of talking with their patients about these thoughts. Therefore, one of the first steps to address this issue is to dare to talk about these topics with the patient. This is also the first step doctors can take to help their patients.

Take a desire to die as a differentiated syndrome Making a differential diagnosis of this syndrome is essential also to find the best ways to help patients. Is it a mere "passive acceptance of death", is it a desire to die, the wish that death comes soon? Or is it a wish toward hastened death, which also may be going into the direction of suicidal ideation or it may be asking your physician for assisted dying or even killing upon request?[18,19] Therefore, there is a clear continuity between a desire to die arising from death and dying distress through to the wish toward hastened death, suicidal ideation, and, as the tip of the iceberg, suicide or wishes for euthanasia.

Once you have established what type of desire to die the patient has, it is important to understand what the communication function expressing this wish is.[20] Does the patient really "mean" it? Or is it a cry for help, a manipulation of the family, a call for attention, an expression of last control in an unbearable acute situation, so the patient does not wish to live like that but does not really want to die?

After the meanings behind such an expression, you have to look for underlying factors.[21] Here the flow scheme of Nissim et al[21] is quite helpful. A desire to hastened death is a common pathway of 2 main syndromes, depression or hopelessness. These syndromes correlate, but of course are not necessarily associated with each other. For all of those, further underlying factors have to be addressed: Is it physical burden? What about self-esteem, what about meaning and peace, what about faith? Of special importance is the psychological personality of the patient regarding

attachment security. Attachment occurs through a positive or negative self-esteem and a positive or negative expectation of the others in front of you. If you have an attachment anxiety, there is a tendency to believe that distress will be overwhelming and support will not be available. If you have an attachment avoidance, there is a tendency to value self-sufficiency and that others cannot or should not be relied on to relieve distress. These forms of attachment styles are risk factors for wishes to die.

Only recently, an international group of experts has consented on a definition of a wish to hastened death: "The wish to hasten death is a reaction to suffering, in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate his or her death. This wish may be expressed spontaneously after being asked about it, but must be distinguished from the acceptance of impending death or from a wish to die naturally, although preferably soon. The wish to hasten death may arise in response to one or more factors, including physical symptoms (either present or foreseen), psychological distress (e.g. depression, hopelessness, fears etc.), existential suffering (e.g. loss of meaning) or social aspects (e.g. feeling that one is a burden)."[22]

The wish towards hastened death and the will to live often coexist! In one of our projects, a patient said "If you had something and I knew it was over in 30 seconds, I will take it", a high wish toward hastened death. The next sentence he said, "I want to live, oh my God!" and he burst out in tears. So it is normal to have 2 paradoxical thoughts at the same time. This can be called double awareness.[23] It is human to think opposite thoughts at the same time, for example, denial and acceptance, hope and despair, being alone and being in community, dying or wish towards hasten death and the will to live. It is our duty as health professionals not to focus on the wish to hasten death but to open up communication again. It is very easy to fall in this "communication trap".[19]

Developing a teaching module In one of our studies,[17] we looked at health care professionals in specialized palliative care and asked them about their experience reacting to patients with the wish to die. We identified quite a few possibilities of responses and of functions of these responses, but the main conclusion was a clear uncertainty and uneasiness and the clear wish to gain more self-confidence.

This was the reason for us to start a project (funded by the Sander foundation) to develop a curriculum and to pilot a 2-day multiprofessional training course for health professionals working in specialized and general palliative care. The primary aim is to enhance self-confidence in speaking with patients expressing a wish to die. The curriculum consists of sharing previous personal experience, talking about the differential diagnosis, the background and the meaning as well as ethical and legal framework. These are discussed in small groups with case vignettes**.** On the second day, health professionals can practice communication in role plays, and we also address the issue of self-care and self-protection.

The main take-home message is that the main reasons for not talking about this issue with patients are thoughts about the "worst case scenarios". What do I do if the patient for instance is acutely suicidal? Thinking this situation through will increase self-confidence. We hope that this teaching course will give more and more professionals the chance to proactively and openly talk about these issues in more confidence, and that this approach will indeed help patients in their suffering.

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