Relevant

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Summaries by Corry den Ouden-Smit

Care in the end of life in practice of young doctors

'LIFE IS NOT FOR ALWAYS, WE HAVE TO REALISE'

Care in the end of life does not get a chance in the medical curriculum say research workers. Medical students should be better prepared for the practice in which they get to deal with death. How do young doctors experience this? Can they be prepared for this anyway?

Teus Lebbing

'I did get communication lessons during my medical training but not about how to deal with death' says general practitioner Stephanie Sondaal (29) 'In practice I learned how to bring the conversation.' Stephanie had to deal with older people during her work on a unit Geriatrics. 'I had to deal with questions around the end of life and dying people. I had to improve my conversation technique. In my opinion the most important thing in the care of life's end is about talking: what is important to them, and to think with them and ask what you can mean to them.'

Loving accompany
'Personal attention and saying that everything is discussible' is also the most important thing in life's end care' says general practitioner Inge Kroese (31), next to the technical aspects like pain relief. During her specialization general practitioner she had enough practice conversation on this subject, too much she thought at that time. But now she sees how important it is. 'Most people die at home and the general practitioner can assist them on their last journey.'
'It is about ''loving accompany'' and knowing the needs of the patient. Does he want to die at home or in a hospice, where is he afraid of, how does he think about euthanasia? I see it works, also in the acceptance by the family, if this is expressed.'

Search
Talking about it is not always self-evident, she sees in her practice. 'Some have thought out everything, others are overwhelmed by my questions. They cannot see reality. Of course a patient has the right to deny but what do you do? Let it be, or do you do your duty as doctor by giving all the information? This is a search no training can give the answer to.'
The same applies to family conflicts and cultural differences. How do you deal with that? Inge: 'I have treated an older Turkish lady with incurable cancer.
Her children did not want us to tell her that. I have talked it over with many a doctor, we wanted to respect their culture but also to inform her and guide her. At last we reached a compromise and with an interpreter we told her she was incurable ill, but not which illness she had.'

Unexpected
For other specialists this topic is different. Rheumatologist Leonard Schoneveld (44, Bravis hospital) understands in the medical curriculum there is little room for conversation technique in life's end problems. 'Doctors are to cure and relieve patients. But when I received, three years ago, a request for euthanasia I was perplex. It was unexpected. I understood her needs, her prognosis was in Faust but this was not what I had in mind becoming a doctor. We talked it over and with help of everybody:

physicians, SCEN physician, nursing team, pharmacy and family I could help her to a dignified end. For me it was a valuable experience. ‘

Failing experience
Oncologist Anouk Jochems (37). ‘What if we cannot cure people? In our basic medical education we are trained in acting and prolonging life and not in accompanying people at the end of their life. By failing experience we go on with prolonging life while it is more important to talk and communicate about their philosophy of life’.

Because Anouk saw the other side of therapy she followed courses on this matter during her specialization as internist- oncologist. Now, working as oncologist in hospital De Haaglanden she is Head of the Team Supportive and Palliative Care that assist colleagues in care for incurable patients at the end of their life. ‘The crucial question in this phase of life is what is important to you? And how can we fill this in? In this way you mark the moment you cannot cure him. And it gives the patient the opportunity to think about his farewell, to try to accept it, to organize things with his family if needed. In this we play an important role.’

Be well prepared
Anouk: 'For doctors it is difficult to enter such a conversation. Not everyone can deal with death. But in most hospitals there are palliative teams that can assist them. To be well prepared a young doctor should get lessons in care of life’s end already in basic medical education. I know those years are stuffed with medical know-how but it is worthwhile if students, in this period, face this fact of life.’ General practitioner Inge Kroese states: ’A doctor should have realistic expectations about his role. Every doctor wants his patient to die in peace. But that is not always possible. Sometimes you cannot relieve pain, itching or the oppressed feeling, often because the patient wants to stay alert, or refuses palliative sedation. I make this a point to be considered to the patient and the family, so they can face up to reality. Because like birth also death is not always beautiful.’

The article End-of-life care in the Dutch medical curricula by Josefien de Bruin, Mary-Joanne Verhoef, Joris P. J. Slaets and David van Bodegom, September 5, 2018 published in the scientific journal Perspectives on Medical Education, can be found on:
https://link.springer.com/article/10.1007/s40037-018-0447-4

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Psychologist René Diekstra wants an another way of talking about death and assisted suicide

‘THE WORD SELF-MURDER SHOULD BE BANNED ABSOLUTELY’

‘I think suicide and assisted suicide will become more rule than exception’ says psychologist, author and emeritus professor doctor René Diekstra. Recently his book Leven is loslaten (Life is to let go) has been published, a book about ‘death with a great future’,

Marijke Hilhorst

A death with a great future, what exactly do you mean by that? • ‘I expect the number of people who want to decide when and how they want to die will grow the coming decennia and even grow considerably. That has to do with the fact people grow older, become tired of living and the wish to self-determination becomes normal. I forecast suicide and assisted suicide will become more rule than exception.’

What do you want to achieve with this book, which looks like a pamphlet? • 'I pursue three goals. That there will be spoken on a different way about death and suicide; make clear we can learn from other cultures and other times about (assisted) suicide; that (assisted) suicide is not a medical-ethical issue but can be executed on a careful and safe way by non- medical persons.

It is also a semantic question (ed. in the Netherlands) where the word self-murder is used instead of self-killing. The word self-murder dates form the fifth century till late nineteenth century. Ending one's life was seen as asocial and antisocial and the one who tried, or committed, suicide was seen as a criminal and punished in a gruesome way. While in the time of the Egyptian pharaoh's suicide was seen as an acceptable, and in certain cases a preferable choice.
Prof. doctor. Nico Speijer – who committed suicide in 1981, at an advanced age, together with his wife out of free will and well-considered- became known by his publication of 1969 with the title The self-murder issue. One year before his death we published a book Help in self-killing. In his farewell letter to me he emphasized to use the word self-killing instead of self-murder. I have taken up this request.'

Isn't it a purely semantic issue? • 'Absolutely not. For the next of kin it is very painful when someone out of their midst is called a ''self-murderer,'' Talking about help in self-killing feels different from help in self-murdering. Murder is a wrong term, for ending your life willfully is not a crime. Since in earlier times suicide has been a criminal act assisted suicide became punishable also. Suicide is not punishable anymore but assisted suicide is. That is crazy. I have started a petition to ban all organizations with the name self-murder in it from governmental subsidy.'

You find assisted suicide can be done by non-medical persons and that this happens already. But by law this is punishable is not it? • 'Years ago I was on a committee to assist caregivers who had received a request for assisted suicide. The committee had been installed by the NVVE and the Humanistic Society. We got cases from doctors, psychiatrists, psychologists and non- medical persons. We talked this over and gave advice to the caregiver. We did in advance what the controlling committee euthanasia does afterwards. Our advice -even if negative- meant support and set their mind at ease. They knew we should stand behind them if trouble came up. An example: if a young person asked for assisted suicide we often advised the contract –approach. To try out treatments not yet tried out. If the treatment did not had effect the caregiver would help out. We have documented all cases into detail. Two things strike out. In the contract-approach most people did choose for life. And ultimately justice did not take legal action against the caregiver. They knew it would be hard to settle the case since we were involved.'

Why doesn't the committee exist anymore? • 'The club has been discontinued because NVVE and Humanistic Society could not agree about continuation. It is a pity. It asks courage to help in assisted suicide. And the juridical consequences can be far reaching. See the case Albert Heringa. I think the way justice has handled this case is reprehensible and a backsliding in civilization. But also I am astonished not more people have reacted against it. It seems society has softened up. More resigned. Also the NVVE should be more active, incite their 167.000 members to send every day an email to the judiciary with the slogan ''Leave Albert Heringa in peace'' You will see what happens!'

You object bringing assisted suicide under the euthanasia law. • 'Absolutely. Euthanasia is no death cause but a qualification of the dying process. Death by assisted suicide is death by suicide. Do not call it euthanasia. Of course the list of assisted suicides will become longer but the image of the proportion becomes clearer. And also the argument to make assisted suicide in principle punishable is a philosophy of life argument.'

At the one side you dedicate yourself to prevent suicide at the other side you say it is wise not to prevent it. That puzzles me. • 'If you prevent a person from committing suicide, if it was a well-

considered decision you can do that unpunished. I find that serious. Especially if that was a wise decision you have to respect that. Surely if continuation of life will be undesirable and without perspective because the quality of life is deteriorated.
In Life is let go I describe how an aged friend of me, a respected mentor, took such a wise decision and I could let him go in loving care. In Utopia of the English humanist Thomas Moore, from 1516, we see that persons who think their life has become without perspective - for whatever reason- should be listened to by the mastery and clergy. Those people get assistance in ending their life. There is one ''but''. The choice to end one's life should be made in concordance with and approval of others. If that does not come off then the death is ''indecent'', as Moore calls it.'

You describe 'preventive suicide' as a decision to end life before the real distress starts. You think people can assess that moment correctly 'especially if they are together' • 'If I had the choice, my preference would be to die together with my wife, if the way how would be acceptable to my children. But imagine she is so ill she does not want to go on living, that I would say I will not go on alone, and my children would point how healthy and vital I still am? How worth full my life, also for them, still could be? Then I do not know what I would do.'

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Investigation: assisted suicide (deadly drink) is good alternative for euthanasia (infusion or injection)

CHOICE IS TO PATIENT AND DOCTOR

The guidelines for doctors and pharmacists is clear: 'The starting point is euthanasia should be effective and safe. The patient has to die within a short period and has to be unconscious of the dying.' What is the best method to realize this? Giving means by injection or infusion? Let him swallow a deadly drink?

Leo Enthoven

The injection- and infusion method are seen juridical as euthanasia, the drink-method as assisted suicide (as). The probe-method is not used often and we will leave this out. In the guidelines of the KNMG/KNMP (ed.: the medical- and pharmaceutic associations) I executing euthanasia and assisted suicide both the KNMG and the KNMP have a preference for the infusing method. Oral intake has too many drawbacks, like vomiting, not drinking fast enough, and slow stomach passage like in patients who have taken opioids (ed.; painkillers) for a longer period. 'It takes much longer to become in coma and die' conclude KNMG and KNMP. That is why they do not prefer the oral method.

Ultimo expression of will
Some doctors have a different opinion with the KNMG/KNMP-preference. They find if the patient takes the drink himself this is the ultimate expression of his will. Also it is less burdened to give not the deadly means themselves, find some doctors.
Pieter Jan Stallen, emeritus professor applied psychology, and Michiel Marlet, general practitioner and SCEN-physician some time ago, find this also.
They analyzed 226 cases of assisted suicide and have published this in the journal of the Dutch Medical Association (NTvG). Later on they looked into 279 as cases which had been analyzed by the Regional Controlling Committee's Euthanasia (RTE's).
Marlet had also a personal experience with assisted suicide, five years ago. A patient, 56 years old, had all kind of ailments, none fatal. She wanted to die. 'I was not eager to help out, but she suffered a lot from the compilation of ailments so I said I wanted to assist but only if she took the deadly means herself. She agreed to that.'

Indian tales

A woman was suicidal a long time. She had bought deadly means in China. Her son became angry when she told him. He said: 'Mother I do not want to have anything to do with this. If you ask a doctor to help out I will assist you.' Marlet looked into the Chinese medication and saw a lot of Indian tales based on unknowingness, nearly failures and fear from doctors. He had seven conversations with the patient. A SCEN- physician did his job. The whole procedure took nine months. She took the deadly drink, sitting between her son and his wife. Before she had received means against vomiting. Within twenty minutes she died. The RTE's judged his course of action 'careful'.
Hereafter he could not let go the subject. He looked up data about the method, searched for cases of assisted suicide, and heard Indian tales. With Pieter Jan Stallen he analyses 226 as- data given by three general practitioners and four medical specialists. They published their findings in the NTvG.

They concluded death set in as fast in the injection method as in the drinking-method. This gave room to other aspects of the euthanasia process like own responsibility, preference of the doctor which method to use, and the possible effects on the nearest of kin. The RTE's have received 6.585 mentions in 2017 of which 279 assisted suicide (102 times cases of accumulation of ailments in old age)
Stallen en Marlet have analyzed these cases also. In six of seven cases death came within half an hour. In 29 of the 279 cases the doctor had to finish up with intravenous medication because death did not came in. In a reaction the KNMG states: 'Oral intake is a method doctor and patient can choose for. No discussion about that. The guidelines for oral intake of a barbiturate drink are clear. But the method is not suitable for all patients. At the moment a committee is busy to actualize the 2012 guidelines. All new facts and insights will be taken in. Of course we will take to heart the research and findings of the two doctors who published in the NTvG. The first half of 2019 we expect the guidelines to be ready.'