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Importance of awareness of patient's views regarding death

Five views of dying

Authors:

- E.C.M.M. Donkers, physician community medicine, managing director Transmuraal Netwerk Midden-Holland
 - E.A.P.M. Thewessen, physician, Board of Directors De Riethorst Stromenland
- Both authors are member of the Board of Stichting STEM (Dying in your own way)

Whereas some patients¹ personally register their imminent death, others push the subject away or continue to search for a cure. Others again place their trust silently in family or religion. If carers are aware of this, it improves their communication with their patients.

The Motivaction research agency has studied the differences in personal views regarding the end-of-life stage. The study was commissioned by the Transmural Network for Central Holland, a cooperative of nursing organisations in the Gouda region, which believes that the available range of care must never form a barrier to the place where a patient wishes to die and that the personal wishes must always be taken into account. However, many people, including carers, cannot cope with the discussion about death. In order to bridge such a gap, we need to know people's views on their end-of-life stage and how they can best be approached. The Motivaction study is part of the STEM project (STEM is Dutch for Dying Your Own Way), aimed at improving communication with the patient in their terminal phase, and subsidised by the national Transition programme for long-term care.

Study of diversity

The Motivaction study was based on Mentality, a research model that groups people in terms of their attitude to life and personal values orientation. The Mentality model distinguishes between three values: Traditional – aimed at conservatism, modern – aimed at possession and pampering, and post-modern – aimed at development and experience. A total of 1570 people reacted to statements regarding their attitude towards the end-of-life stage and to questions regarding their needs and behaviour. The sample group thus acquired is representative of Dutch people from 18 to 80 years in terms of the variables: age, gender, education, region and values orientation (Mentality environment). The questionnaire was formulated on the basis of literature and in consultation with nursing professionals, and was tested beforehand, particularly because of the unusual subject. The responses showed that people vary in the way in which they view and handle their end-of-life stage. The variations concerned the degree to which there was:

- taboo, interpreted as fear and helplessness;
- socialised dying, interpreted as closeness to family and friends;
- talking and thinking about death, interpreted as adjustment and acceptance and
- control of the end-of-life stage, interpreted as autonomy and manipulability.

The respondents were grouped in five different segments, based on the way in which they dealt with these four dimensions. Each segment shares as many similarities as possible within the group and contrasts as much as possible in relation to the other

¹ *Patients should be taken to mean clients, residents and their families*

segments. These STEM segments vary in their view of daily life and in the way in which people deal with their end-of-life stage (see figure).

Styles of dying

The five different STEM segments or styles with which people deal with the end-of-life stage can be typified as pro-active, open-minded, trusting, rational and social.

Pro-active people (18% of respondents) are more often female than male; are spiritual but are less often a member of a traditional religious community. They are strongly socially involved and want to remain useful until the end. They are more likely than others to have experience with bereavement, caring and (volunteer) work in the care sector. Death is not a taboo for pro-active people. They want to decide for themselves regarding their end-of-life, and wish to retain their dignity, independence and sense of control. Of all five segments, this group has made the most arrangements in terms of will, medical statements and insurance.

Open-minded people (22%) are more often male than female. They are young, tolerant and oriented towards friendships rather than family. These people have lower than average spirituality or religious beliefs. They want to enjoy life, explore new boundaries, and they have explicit own ideas. They have relatively little experience with bereavement. Death and possible infirmities are banished from their perception. If there is awareness of the end-of-life stage, open-minded people like to give it a personal touch.

Trusting people (12%) are more often than average married and of a religious nature. The family is important. They attach great importance to rules and to a sense of duty. People from this segment are more likely than others to provide care for those close to them or to work in the care sector. Death is seldom a conversation topic because it is a part of life. Trusting people feel less fear for the end-of-life stage. They feel supported by their religion and their loved ones. They want to have the opportunity to say goodbye. There is a clear need for mourning rituals.

Rational people (15%) are more often male than female and are less religious or spiritual. They work hard and attach great importance to looks and status, they follow trends and believe in the manipulability of life. These people are oriented towards friendship and family but seldom take on the carer role. Rational people admit that death is a taboo for them. They have difficulty showing their vulnerability, and tend to hold onto their rational approach. Medical care, privacy and objective information is important.

Sociable people (33%) are the largest group, with an overrepresentation of people of pensionable age. They are often affiliated to a church but are not deeply religious. This segment is characterised as working-class, with a carefree lifestyle within set frameworks. They are sensitive to hypes. Sociable people appreciate the company of friends and family. There is a strong degree of denial regarding death. At the same time, they foresee a 'grand and majestic send-off' for themselves and others.

Initial experiences

There are no objective, all-inclusive criteria for the segments. It is a question of intuition and empathy. Most carers introduced to the five STEM segments immediately recognise their own style and subsequently take a fresh look at their patients. A small group of carers has difficulty with the segmentation and regards it as a form of pigeon-holing. In Central Holland, reflection meetings have been initiated for doctors, nurses and carers, in which the STEM segments are depicted by actors. Participants learn to explore their

own reference framework and its influence on communication with the patient. A GP: 'Knowledge of your own views on the end-of-life stage gives you extra patient orientation in your work.' A second learning aspect is the awareness that people can vary fundamentally in their opinions regarding the end-of-life stage and that not everyone feels the (same) need to talk about death. A carer: 'Death is a part of life. You don't need to talk about it at length. I'm most attracted by the trusting segment. Only now do I realise that less than 15 percent of the population shares my opinion.' The STEM segmentation has also proven itself a good instrument when the patient and their loved ones have different opinions (see case study). A specialist may realise that he requires more variation in his bringing of bad news. 'Not everyone requires factual information and empathy with their feelings, and not always all at once. Pro-active patients are generally well informed but want to know all about alternatives. They make their own clear choices in terms of care. Rational patients are less well informed on the other hand. They have a need for factual information. Very practical and concrete, with clearly defined pros and cons. Rational patients want to hear about opportunities, but not make a choice themselves.'

The five STEM segments of styles of dying show a diversity of personal opinions. People differ in what they believe to be important, also in this final stage of life. Knowledge of the differences in personal preferences gives clarity on the way in which people are preferably approached. This provides support for better communication with the patient. The initial experiences in practice confirm this theory.

Case study

A young woman without any prior medical history is shown to have extensive metastasis of an unknown primary tumour. 'It's progressing fast, I'm afraid I don't have long to live', she says. She is in a hurry to make all the arrangements for the end of her life. Her husband has problems with this. He is holding onto hope and would prefer to banish the idea of her dying. When the time really comes, that will be early enough to discuss what's needed. During treatment, the medical personnel needs to keep encouraging the patient to fight. The husband is also called upon to help but he is sandwiched between his wife's statements and the instructions given by the personnel. He would prefer to follow the approach taken by the personnel but is aware that he will then lose contact with his wife. One of the nurses is familiar with the STEM segmentation and recognises the rational approach of the hospital versus the pro-active style of the patient and the more open-minded attitude of the husband. She discusses the husband's confusion and helplessness with him. He decides to open up to his wife's signals, in which he has the most faith, despite his hopes otherwise, and to prepare himself for what is to come, together with her. The patient went home a few days later, with the necessary supervision, and died a week later. 'The worrying was over, even though she was close to death. There was peace in the house and we were able to support and comfort each other', the husband explained later.

Summary

- People have different views of death and tend not to talk about them. That makes it difficult to discuss the care required at the end-of-life stage.
- Motivation applied values orientation to make a representative survey of the personal opinions of people regarding the end-of-life stage, and distinguished five different segments.
- Each segment has its own style of coping with death.
- Insight into the various segments and personal value orientations helps carers to improve their communication with patients, when presenting bad news for example.