Spiritual care in the intensive care unit

Dr. B.J.C. Giebner
Spiritual Care Team, Academic Medical Center Amsterdam, the Netherlands

Correspondence
b.j.giebner@amc.uva.nl

Keywords - critical care, spirituality, end of life, quality of care, multiprofessional care, secularisation

Abstract
The title of the article by Suzan Willemse Spiritual care in the intensive care unit: an integral part of daily intensive care?, in this issue of the Journal, suggests that spiritual care should be integrated in the highly technical care on the ICU. At the same time, it gives rise to the following question: Isn’t the main purpose of spiritual care to give relief in the last moments of life or only intended for patients with religious questions? In her article, Willemse shows that spiritual care has more to offer and is a natural supplement at the operational level.[1]

I agree with this approach and place the emphasis on the broad basis of spiritual care as focussed on giving meaning to life experiences. In the first instance, spirituality would seem to be a concept from another, higher world. After all, we find it easier to talk about the psychological mechanisms that we employ or the coping strategies we use.[2] What is important for us and for patients is autonomy, empowerment and the striving to maintain control of the situation. Based on the right information and our own strategies, we believe we will reach our goal.

This is exactly what spiritual care focusses on: What is my goal? And what meaning does this information have for me? For example, for the son of a very ill elderly mother, what is the value of admitting or not admitting her to the intensive care unit or administering invasive supportive therapy or not? Spiritual caregivers work within this dimension of values and meaning. As Willemse says, spiritual care is ‘interrelated with physical and psychosocial care’.[3] I put the emphasis on the creation of meaning. It is the spirit that makes the difference. It is this dimension that makes a human a ‘person’.[4] A person who is more than just a well or poorly functioning physical, psychological or social mechanism. For an ICU patient the role of the relatives is of great importance in these deliberations, whereby they try to interpret the values of the patient.[4]

But what does meaning and value have to do with spirituality? By value, we mean that which we think is worth fighting for.[5] The Latin ‘spiritus’ refers to the inner self - the striving of people towards or from these goals. Spirituality can then be defined as ‘The aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred.’[6]

The spiritual caregiver focusses explicitly on this spiritual dimension, on the patient as a person. All the other care caregivers do this too, at least implicitly.[7] Each professional is, after all, not only paying attention to the functional dimension or following the guidelines. It is common practice for professionals, individually or as a team, to make efficient and effective choices which they themselves also support as a person (‘I am dedicated to doing this’, ‘I cannot justify this’, ‘this is (not) quality of life’).[8] I recall a trauma victim, a young tourist, who was on her own. Only after an extensive discussion between caretakers on the risks of and need for amputating her second leg, was this difficult decision made. The medical prospects, professional values, the values of the patient and the personal values of the professionals were all taken into consideration. Spiritual caregivers are trained in clarifying the values of those involved in such deliberations and in facilitating the discussion. In this way, dilemmas became manageable and responsible choices can be made.[9]

In these discussions, attention is given to looking for and discussing the things that matter to people – in their lives and at the moment of admission to the ICU – with an eye to human dignity and shared humanity. Nurses and doctors pay attention to this important dimension, either themselves or by suggesting, for instance, that the family of a dying mother talk to a spiritual caregiver. The spiritual caregiver invites those present to sit
around the table. Everyone is given the opportunity to say who mother (grandmother, wife …) was for them. In this gathering, insights may emerge that other family members have not heard before: the good and less good things about what mother meant to everyone. This gives the family strength and a feeling of closeness.

The spiritual caregiver has a role of witness and coordinator here. His added value is that he is from the hospital but outside the actual treatment management. He is someone who pays attention to the experiences of people. His questioning and understanding provide peace of mind. Patients are more than just a life-threatening illness, they have a story.[10-12] They have interests, needs, longings. They are sometimes striving for something that goes further than their direct physical wellbeing. For example, a person may be sad that he has had to leave his father uncared for, while he himself is reduced to a care-dependent patient. He experiences relief if he can share his concern with someone.

Understanding has a very supportive and harmonising effect. This often becomes clear on the ICU in relation to life-threatening and religious values. In the case of conflicting viewpoints tension can arise, sometimes due to prejudices from both sides. Spiritual caregivers help to promote good communication. They can clear up misunderstandings and enable consensus to be reached. For example, decisions concerning stopping the treatment of patients with an Islamic background can lead to differences in interpretation and emphasis, resulting in an impasse. An eye for quality of life, the principles of wellbeing and doing no harm should be aligned to the value of preserving life and differences of opinions about autonomy and consensus. Often, on reflection, words can create misunderstanding, while all parties may actually agree on the underlying principles.

In crisis situations, such as a stay on the ICU, people experience distress and look for answers to practical but also inner questions. ‘Does my life still have meaning?’ ‘What am I inflicting on my wife?’ Patients sometimes feel alone. The people surrounding them often want them to think ‘positively’, that they are doing better or at least that it is physically bearable. Spiritual caregivers want to bear the burden with the patient in his existential distress.[13] The fears, the sadness, the emptiness are real and cannot always be taken away. They are part of life. If a person feels understanding for his situation and that he is not alone in this experience, this can ‘make a difference’. Patients indicate that sharing this experience is of priceless value.[14] This is about the little things (the nurse’s hand on the patient’s arm), when an experience is shared.[19] As travelling companions,[31] spiritual caregivers support patients during their existential journey on the ICU.

References