Spiritual/ existential care of terminal ill patients: how is it documented in a palliative care in-patient unit in Västerås, Sweden?

Course project for the Nordic Specialist Course in Palliative Medicine 2017-2019. Stephanie Strubel /Tutor Margareta Randén, PhD

Background

Palliative care, according to WHO, should meet physical, psychological, social and spiritual or existential needs. Cicely Saunders, the founder of the modern hospice movement defined the concept of total pain. The concept of total pain describes pain not only as a physical experience but also as social, emotional and spiritual/ existential distress which together contribute to suffering. The concept of total pain and the crucial importance of spiritual care illuminates very clearly that palliative care requires a holistic view of the dying individual. It is an ongoing question if this goal is met in clinical practice.

Spiritual care is, according to the EAPC, multidimensional and consists of existential challenges like questions concerning identity, meaning, suffering, death, guilt, shame, reconciliation, forgiveness, freedom, responsibility, hope, despair, love and joy. Spiritual care consists also of value based considerations and attitudes like what is most important for each person, such as relation to oneself, family, friends, work, things nature, art, culture, ethics, morals and life itself. Religious considerations and foundations like faith, beliefs and practices, the relationship with God or the ultimate belong to spiritual care as well.

The Palliative Care Unit in Västerås, Sweden is a ward consisting of 15 beds for an uptake area about 270000 inhabitants. The ward is open for all adult patients in need of palliative care, regardless of diagnosis. However most patients who come to the ward have a cancer diagnosis. There are about 200 deaths per year at the Palliative Care Unit in Västerås.

Aims and objectives

The aim of the study was to evaluate the incidence of spiritual/ existential care for each patient according to the medical records and to map by whom (doctor, nurse, assistant nurse), how many times the spiritual/ existential care was documented and which dimensions of spiritual care according to the EACP-definition were documented for each patient.

Methods

The study was performed retrospectively. It was a mixed quantitative and qualitative analysis. 100 medical records of patients who died at the Palliative Care Unit in Västerås were reviewed with start date 31 December 2017 and back in time. Each medical record was reviewed 3 months back in time or shorter, depending on how long the patient lived.

Results

Of 100 patients, 38 patients had a total of 62 spiritual/ existential conversations. 62 patients had no documented spiritual/ existential conversations. 21 patients had 1 conversation, 11 patients had 2 conversations, 5 patients had 3 conversations and 1 patient had 4 conversations. Of the 38 patients who had a conversation, 23 were women and 15 were men. The 100 patients were between 29 and 96 years old (median 75.5). For all 100 patients the care period at the palliative care unit was total 1355 days, minimum 1 day, maximum 90 days, median 7 days. 34 conversations were conducted by the doctor, 24 by the nurse, 3 by the assistant nurse and 1 by the social worker.

Short discussion

Considering that the 100 patients who died, died at a specialist palliative care unit, the number of 38 patients who had a spiritual/ existential conversation seems to be rather low. Considering that the staff members of a palliative care unit are well-trained when it comes to difficult conversations, an explanation of the low number would be that these conversations not always are documented in the patient´s records. Another explanation would be that the patients feel that these issues are taboo. They dare not talk about it and the staff does not actively ask for such thoughts.

Conclusion

The staff at the palliative care unit need to become more aware when they have spiritual/ existential conversations and how these are documented. The staff may need to be more active in addressing these issues.