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REVIEW

Spiritual care in the intensive care unit: an integral part of daily intensive care?

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Abstract

High-tech components such as drug therapy, mechanical ventilation, renal replacement therapy and many kinds of monitoring characterise day-to-day care in the intensive care unit (ICU). They yield the impression of safety and control, to reassure patients' uncertainties, pain, bereavement and agony. Naturally, doctors and nurses give priority to maintenance of the clinical aspects. However, the primary focus on the treatment of clinical symptoms may impede the understanding of the spiritual needs of patients. A life-threatening disease may lead to an existential crisis with patients and their relatives. Consequently, questions related to their beliefs and worldview arise. Spiritual caregivers can play a complementary role in meeting spiritual needs within whole patient care. However, structured and protocolled spiritual care is scarce. In this review we highlight a more or less unexplored area of ICU patient care and intend to encourage spiritual caregivers to get increasingly involved in routine ICU care.

Introduction

The Dutch Association for Spiritual Caregivers defines spiritual care as follows: giving professional, intensive guidance, support and advice in the search of the meaning of illness and matters related to worldview, and coordinating and structuring all of this. Existential, spiritual, ethical and aesthetic issues that arise, belong to the domain of the spiritual caregiver.[1]

The role of a spiritual caregiver was obvious until a few decades ago: the professional execution of ecclesiastical tasks. Secularisation on one hand and reorganisations within healthcare on the other hand rapidly changed that situation.[2] We will briefly discuss both factors.

First of all, research has shown that predominantly Protestant countries in North and West Europe are more subject to secularisation than Roman Catholic countries in southern Europe or Eastern Orthodox countries. Secularisation can be defined as: reduction of religiosity, limitation of the radius of religion and adjustment of religion to secular ideas.[3] Secularisation also follows a different path in the USA. According to Heitink, religion is regarded as a binding social force there while church communities take care of their members and reach out to people in need of support and shelter.[4] In Europe this is less the case, partially because of the social and healthcare systems.[5]

In contemporary Dutch healthcare, a reinterpretation of the role of a spiritual caregiver is desirable; it is important that spiritual care goes along with the aforementioned change in society. According to some authors, this reinterpretation should be characterised by a wider context that links up with the search for religiousness, as appears from studies.[2,5-7]

A spiritual caregiver who works in the intensive care unit (ICU) meets patients and their relatives who are going through a crisis. By defining his own role in the search for ways of coping with such a crisis,[8] the spiritual caregiver can make a meaningful contribution to integral ICU care. Integral care means that spiritual care is interrelated with physical and psychosocial care and not limited to spiritual rituals.

In this context it may be useful to go into the difference between psychotherapy and spiritual care. The distinction between psychotherapy and spiritual care was described by Mooren in his study into the relation between psychotherapy and pastoral care: for a psychotherapist, psychology is the primary reference and worldview secondary. For the chaplain it is the exact opposite. With him, worldview is the primary reference and psychology secondary.[9] Still, some knowledge of psychology is important for the spiritual caregiver.[10]

Reorganisation within healthcare is the second factor that influences the role of spiritual care; the organisation of Dutch healthcare has changed profoundly in the last decade. The government is withdrawing more and more, and health insurance companies and municipalities are coming into play in healthcare budgeting. Because of budget cuts, there has been a cut down on the expenditure of healthcare facilities. All kinds of supportive disciplines, including spiritual care, are subject to economising.[11]

In our opinion, all of the above requires a change in the mindset of all people involved in daily ICU care.[12]
We suggest change using a two-level approach. Firstly, we call for a fundamental reorientation of the provision of spiritual care in the ICU. Secondly, improvement in delivering spiritual care can possibly be achieved by auditing, performance feedback, education and multidisciplinary team meetings to clarify patient needs and the responsibilities and tasks of the healthcare worker.
Several studies show that, in order to achieve more integrated care, education of the ICU team is essential to change attitudes and to improve the knowledge regarding spiritual care.[13-17]
The aforementioned two-level approach aims to reach a highly integrated provision of spiritual care.
This article aims to contribute to the reorientation of the role of spiritual caregivers in ICUs. In countries where the aforementioned secularisation and economising are taking place or will probably take place in the near future, this reorientation might be relevant while our focus is on the Netherlands.
The following essential spiritual care dimensions will be discussed: tasks of the spiritual caregiver, context of communication in the ICU, search for meaning of illness in the ICU, worldview, quality of life and quality of care.

Tasks of the spiritual caregiver

Patients in crisis situations are admitted to the ICU daily. In this respect there is a possible need for diagnosis and treatment of spiritual distress. On admission a patient's health status is extremely challenged. One may surmise that fear and spiritual needs demand the utmost of a patient. Selby's qualitative research shows that understanding the role of front-line care providers in the identification and management of spiritual distress remains challenging.[18] In appendix 1 of his research, Selby provides healthcare workers with a Healthcare Professional Interview Guide that may be helpful to identify a patient's spiritual needs. Spiritual caregivers are mainly consulted at the request of a care professional. In the ICU the spiritual caregiver can offer a listening presence and may accompany the patient through his illness. The spiritual caregiver gives help in the patient's search for meaning of illness or when the patient's experience of illness or disorder dominates his life.[1] Religious experience may be a part of this search, but is definitely not a requirement. Unlike pastors who pay home visits in their own parish, hospital spiritual caregivers do not need to share the patient's frame of reference.

A recent study shows that a patient's relatives often do not think of the possibility of spiritual care during the process of dying of their loved one. Therefore, it is recommended that ICU nurses ask the relatives about their spiritual needs and involve the spiritual caregiver, if necessary. Moreover, inquiring about the spiritual needs of patients as well as relatives should be done at the beginning and during the ICU stay, not just during end of life care.[19]
At this moment, within the Association of Spiritual Caregivers (VGVZ) there is a call for working methodically in relation to diagnostics and spiritual care provision. Smit investigates the basic methodology of spiritual care in his dissertation Answers To life Itself. The insights of this study are not only important for spiritual caregivers and their supervisors, but also for other care professionals.[20]

Stimulating integrated, multidisciplinary cooperation in the ICU is one of the tasks of well-trained spiritual caregivers. Moreover, they could play a complementary role in supporting healthcare workers after emotionally difficult cases or family-staff disagreement.[21,22]
Considering all of the above, complete incorporation of qualified spiritual caregivers in the ICU staff is strongly advised.[23]

Context of communication in the ICU

An ICU patient on a respirator scribbles the following note to the spiritual caregiver: 'taking a decision – forcing – waiting time – what purpose does it serve?' She also keeps repeating the same gestures in the same order: first she points to herself, then to the spiritual caregiver. Subsequently, her hand moves to her throat and she draws a horizontal line. She wants to share with the spiritual caregiver the moral choice she sees: wouldn't it be better to terminate treatment, maybe even life itself?
A common feature of ICU patients is that they are no longer able to communicate in the usual way due to their illness or treatment (sedation and intubation). Sometimes they are able to hear but can no longer speak. Writing and nonverbal utterances are the only means of communication. Such a situation requires special communication skills, patience and intuition from relatives and caregivers. In those situations, worldview related questions and subtle distinctions might get lost. Transparency about the way the spiritual caregiver communicates with patients and their relatives forms the basis for sound cooperation and coordination with other disciplines. However, spiritual caregivers may withhold transparent communication from other ICU caregivers on the grounds of professional confidentiality. Patients are entitled to confidentiality when it comes to the substance of worldview related matters. Still, they may benefit from an exchange of care-related aspects of their worldview among the caregivers involved, within the framework of shared professional secrecy. Most of the patients and relatives report that interdisciplinary communication is a key component of good ICU care, and might even be of utmost importance in end of life care.[24]

A special element of spiritual caregivers' communication with patients and their beloved is ritual communication. For instance - but definitely not restricted to – a blessing or anointing the sick. In the performance of rituals in ICUs, the spiritual caregiver is challenged to communicate simultaneously with patients, their surrounding loved ones and the – often absent – community at large of the religious tradition. Disregarding any one of these elements may rob the ritual of its significance and hamper patients' search for meaning of illness and worldview.

Search for meaning of illness in the ICU

Investigating spiritual distress means that one has to look into how patients and their relatives deal with the meaning of illness.[25] The 'why is this happening to me' question concerns both cause and purpose. Suffering is exacerbated if patients fear that something in their past could be the cause of their affliction. Spiritual caregivers can make it possible to discuss and/or alleviate such fears. Some patients can find release in entrusting their life story to a spiritual caregiver. Through talks he may help to break down barriers by probing the nature of the obstacle; such conversations are characterised by listening, joint exploration, discussion and consultation.[20]

Worldview

A mother of Afro-American origin sings Christian hymns to her son who is unable to speak. She asks the spiritual caregiver for the lyrics of a special hymn he used to sing as a boy. After some googling, the spiritual caregiver manages to provide her with the lyrics, whereupon she spontaneously starts singing. After a while the boy lets the spiritual caregiver know how he was strengthened during his ICU stay hearing his favourite hymn.

Spiritual caregivers deal respectfully with patients and relatives with diverse worldviews. The worldviews of the latter co-determine the way patients and relatives deal with a crisis. It concerns basic beliefs, key values and a perception of life that enables them to make decisions when necessary, also at an ethical level.[1]

In the ICU the spiritual caregiver is probably the most suitable professional to give patients and their relatives an opportunity to talk about their worldviews. Ethical choices should accord with the person's basic beliefs about the meaning of life, as well as what a dignified death entails.[26] The multicultural diversity of worldviews in the ICU may become particularly evident when opinions on the possibilities and limits of medical interventions differ. If necessary, the spiritual caregiver can/should call in a representative of the relevant culture. Thus, room for various worldviews in the ICU is extremely relevant for both quality of life and care.

Quality of life

A spiritual caregiver's dealing with crisis, death and farewell in the ICU is more effective when related to quality of life in the widest sense.[27] Quality of life is usually understood as being free from pain and unbearable suffering, as well as emphasis on the patient's autonomy. The World Health Organisation defines quality of life as the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment.[28]

In recent times more interest in spiritual coping and even healing as a component of quality of life has arisen.[29] It is surmised that integration of spiritual care positively influences patient satisfaction scores in quality of life questionnaires.[30] Quality of life can be strongly connected to patients' expectations and their outlook on life and death. When a patient does not want to go on, they may find it difficult to say so openly. It is sometimes easier to share this wish with a spiritual caregiver than with relatives or caregivers. Concerning the latter, 'They do their best,' is a phrase which is heard regularly. Spiritual caregivers can help patients to find a clear articulation of their personal vision and express this vision to their relatives and caregivers.

Patients find themselves in crisis, but their loved ones might share their suffering to a greater or lesser extent. Often they are faced with accomplished facts. Often they disagree; they identify with the situation and discover that what is acceptable for one person is not acceptable for another, for example in decisions whether or not to resuscitate. The spiritual caregiver can play a mediatory role by getting the relatives to discuss the possibilities with each other.

Quality of care

At the request of an ICU nurse, the spiritual caregiver is called in the middle of the night. A young woman with a husband and four children will probably die in a matter of hours or a few days. The father states that he doesn't want an unction ritual, he asks the spiritual caregiver for some kind of alternative. When the whole family is gathered round the bed, the spiritual caregiver asks one of the children to read the poem 'I love you' aloud. This meets the father's request to say farewell to his wife in a way that fits their small children's experience of their mother dying.

The intensivist is responsible for all aspects of care in the ICU. Clear communication of the intensivist's vision on care policy with all people involved is very important. Likewise, healthcare workers should communicate their experiences in the ICU during multidisciplinary consultations. At present, spiritual caregivers in ICUs work in a fairly isolated way; their work is hardly based on protocols and their input is restricted.[31]

Spiritual caregivers can contribute in structuring divergences in multidisciplinary consultations.[32] There is growing scientific evidence for the role of spiritual care in quality care.[33,34] Relatives of ICU patients experience greater support in the event of

termination of treatment if there is clear communication and if their spiritual needs are also considered.[35] Moreover, appraisal of care during the last 24 hours of life revealed that relatives were more satisfied with spiritual care if a spiritual caregiver was involved. Significantly, a correlation between satisfaction with spiritual care and the overall experience of intensive care has recently been established.[36]

Addressing spiritual needs should now be considered an important component of multidisciplinary care in the ICU.[37,38]

Conclusion

Spiritual caregivers explore the journey that patients and their relatives make during their stay in the ICU. In ICUs, more than elsewhere, the outcome of this journey is unpredictable. Nobody can dictate to a patient how long they have to persevere. Since ICU patients are so vulnerable and dependent, they require integrated spiritual care and attention, in addition to the high-tech medical care that strikes the eye. In our opinion, spiritual caregivers are travelling companions for patients and their relatives, together with the other caregivers.

We have explored the various dimensions of spiritual care in the ICU. Spiritual care as an integral part of daily intensive care can contribute to the improvement of quality of care and quality of life in the ICU. Quantitative and qualitative research may lead to evidence-based, integrated spiritual care in the ICU.

Disclosures

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References

1. VGVZ. Beroepsstandaard voor Geestelijk Verzorger. [Association for Spiritual Caregivers]. available at http://vgvz.nl/userfiles/files/Over_de_VGVZ/VGVZ_Professional_Standard.pdf 2010.
2. Zock H. The split professional identity of the chaplain as a spiritual caregiver in contemporary Dutch health care: are there implications for the United States? JPCC. 2008;62:137-9.
3. Dekker G, Stoffels HC. Godsdienst en samenleving. [Religion and society]. Kampen, the Netherlands. Kok 2011; 9th ed. pp 124-50 (In Dutch).
4. Heitink G. Golfslag van de tijd. [Billow of the times]. Utrecht, the Netherlands. Kok 2012; 3rd ed. pp 208,220-30 (In Dutch).
5. Schilderman JBAM. Religie en zorg in het Publieke Domein.[Religion and care in the Public Domain]. In WHBJ van den Donk et al., Geloven in het Publieke Domein [Believe in the Public Domain] WRR rapport no 13. Amsterdam, the Netherlands: Wetenschappelijke Raad voor het Regeringsbeleid [Scientific Council for Government Policy] 2006 (In Dutch).
6. Bernts Y, Berghuijs J. God in Nederland 1966-2015 [God in the Netherlands 1966-2015]. Utrecht, the Netherlands Ten Have 2016 (In Dutch).
7. Ganzevoort RR. Forks in the Road when Tracing the Sacred. Practical Theology as Hermeneutics of Lived Religion. Presidential address to the Academy of Practical Theology, Chicago 03-08-2009 (Internet:http://wwwruardganzevoortnl/workhtml#2009.
8. Ganzevoort RR, Visser J. Zorg voor het verhaal; Achtergrond, methode en inhoud van pastorale begeleiding.[Care for the story; Background, method and content of pastoral guidance]. Zoetermeer, the Netherlands, Meinema 2009; 2nd ed., pp 290-305 (In Dutch).
9. Mooren JHM. Geestelijke Verzorging en Psychotherapie. Godsdienstpsychologisch onderzoek naar de verhouding tussen psychotherapie en pastoraat.[Spiritual Care and Psychotherapy. Religion Psychological research into the relationship between psychotherapy and pastoral care]. Utrecht, the Netherlands, De Graaf 2008; 3rd ed (In Dutch).
10. Hijweege NM. 'Wat betekent dat?' en 'Waar staat dat voor?' Over de samenwerking tussen geestelijk verzorger en psycholoog. [What does that mean? and What does it stand for? About the co-operation between spiritual caregiver and psychologist. Psyche Geloof. 2010;21:196-21 (In Dutch).
11. Krabbe-Alkemade YJ, Groot TL, Lindeboom M. Competition in the Dutch hospital sector: an analysis of health care volume and cost. Eur J Health Econ. 2016. DOI: 10.1007/s10198-016-0762-9
12. Kortner UH. Spiritualitat, Religion und Kultur auf der Intensivstation--wie vertragt sich das? [Spirituality, religion and culture on the intensive care unit--how are these compatible?]. Wien Klin Wochenschr. 2009;121:230-5 (In German).
13. Benito E, Oliver A, Galiana L, et al. Development and validation of a new tool for the assessment and spiritual care of palliative care patients. J Pain Symptom Manage. 2014;47:1008-18.
14. Ho LA, Engelberg RA, Curtis JR, et al. Comparing clinician ratings of the quality of palliative care in the intensive care unit. Crit Care Med. 2011;39:975-83.
15. Balboni MJ, Sullivan A, Enzinger AC, Epstein-Peterson ZD, Tseng YD, Mitchell C, et al. Nurse and physician barriers to spiritual care provision at the end of life. J Pain Symptom Manage. 2014;48:400-10.
16. Gijsberts MJ, van der Steen JT, Muller MT, Hertogh CM, Deliens L. Spiritual end-of-life care in Dutch nursing homes: an ethnographic study. JAMDA. 2013;14:679-84.
17. Noome M, Beneken Genaamd Kolmer DM, van Leeuwen E, Dijkstra BM, Vloet LC. The role of ICU nurses in the spiritual aspects of end-of-life care in the ICU: an explorative study. Scand J Caring Sci. 2016. doi: 10.1111/scs.12371.
18. Selby D, Seccaraccia D, Huth J, Kurrpa K, Fitch M. A Qualitative Analysis of a Healthcare Professional's Understanding and Approach to Management of Spiritual Distress in an Acute Care Setting. J Palliat Med. 2016;19:1197-204.
19. Noome M, Dijkstra BM, van Leeuwen E, Vloet LC. Exploring family experiences of nursing aspects of end-of-life care in the ICU: A qualitative study. Intensive Crit Care Nurs. 2016;33:56-64.
20. Smit J. Antwoord geven op het leven zelf. Een onderzoek naar de basismethodiek van de geestelijke verzorging. [Answers to life itself A study into the basic methodology of spiritual care] Delft [The Netherlands] Eburon Academic Publishers 2015 Dutch.
21. Schenker Y, Crowley-Matoka M, Dohan D, Tiver GA, Arnold RM, White DB. I don't want to be the one saying 'we should just let him die': intrapersonal tensions experienced by surrogate decision makers in the ICU. J Gen Intern Med. 2012;27:1657-65.
22. Forster E, Hafiz A. Paediatric death and dying: exploring coping strategies of health professionals and perceptions of support provision. IJPN. 2015;21:294-301.
23. Choi PJ, Curlin FA, Cox CE. 'The Patient Is Dying, Please Call the Chaplain': The Activities of Chaplains in One Medical Center's Intensive Care Units. J Pain Symptom Manage. 2015;50:501-6.
24. Curtis JR, White DB. Practical guidance for evidence-based ICU family conferences. Chest. 2008;134:835-43.
25. Loscalzo MJ. Palliative care and psychosocial contributions in the ICU. Hematology Am Soc Hematology Educ Program. 2008:481-90.
26. St Ledger U, Begley A, Reid J, Prior L, McAuley D, Blackwood B. Moral distress in end-of-life care in the intensive care unit. J Adv Nurs. 2013;69:1869-80.
27. Long AC, Kross EK, Engelberg RA, et al. Quality of dying in the ICU: is it worse for patients admitted from the hospital ward compared to those admitted from the emergency department? Intensive Care Med. 2014;40:1688-97.
28. WHOQOL. Measuring Quality of Life available at http://www.who.int/mental_health/media/68.pdf. 1997.
29. Park CL, Sacco SJ. Heart failure patients' desires for spiritual care, perceived constraints, and unmet spiritual needs: relations with well-being and health-related quality of life. Psychol Health Med. 2016:1-10.
30. Hughes B, Whitmer M, Hurst S. Innovative solutions: a plurality of vision--integrating the chaplain into the critical care unit. Dimens Crit Care Nurs. 2007;26:91-5.
31. Handzo GF, Cobb M, Holmes C, Kelly E, Sinclair S. Outcomes for professional health care chaplaincy: an international call to action. J Health Care Chaplaincy. 2014;20:43-53.
32. Jensen HI, Ammentorp J, Johannessen H, Ording H. Challenges in end-of-life decisions in the intensive care unit: an ethical perspective. J Bioeth Inq. 2013;10:93-101.
33. Fitchett G. Making our case(s). J Health Care Chaplaincy. 2011;17:3-18.
34. Fitchett G, Nieuwsma JA, Bates MJ, Rhodes JE, Meador KG. Evidence-based chaplaincy care: attitudes and practices in diverse healthcare chaplain samples. J Health Care Chaplaincy. 2014;20:144-60.
35. Gries CJ, Curtis JR, Wall RJ, Engelberg RA. Family member satisfaction with end-of-life decision making in the ICU. Chest. 2008;133:704-12.
36. Wall RJ, Engelberg RA, Gries CJ, Glavan B, Curtis JR. Spiritual care of families in the intensive care unit. Crit Care Med. 2007;35:1084-90.
37. Festic E, Wilson M, Gajic O, et al. Perspectives of Physicians and Nurses Regarding End-of-Life Care in the Intensive Care Unit. J Intensive Care Med. 2012;27:45.
38. Puchalski CM, Blatt B, Kogan M, Butler A. Spirituality and health: the development of a field. Acad Med. 2014;89:10-6.