

UDC: 614.253.5:616-053.2(497.115)

THE NURSES ROLE IN PALLIATIVE CARE WITH CHILDREN IN SEVERE HEALTH CONDITIONS

Blerta Vuçitërna¹, Krenare Shehu², Arbona Sadiki², Arlinda Maloku², Filize Aliu²

Clinical centre University of Kosovo, College of Medical Sciences “Rezonanca”

Received: 2017-03-10

Accepted: 2017-04-20

Published online: 2017-04-30

Introduction

Nowadays palliative care in children has become more complex due to the health conditions and also in the view of the complexity of psycho-social care. Pediatric palliative nursing care is both stressful and rewarding, and it requires coping skills, confidence, and other attributes for successful patient care and nursing practice.



Materials and Methods

In a period of 6 months in 2016, palliative care was studied at the Pediatrics Clinic in Prishtina, University Clinical Center of Kosovo, which describes our experience of nurses caring for dying children and also exploring the impact of providing palliative care to the hospital staff, in order to seek possible best care and to influence more positively to patients' care and nurses job satisfaction and retention.



Results

Based on our experience, a qualitative and focused group, we tried to find out the most common problems of children suffering from severe neurological disease.

The study started at the beginning of the year 2016 during the period January-June 2016 and this type of study is retrospective. All nurses were asked to answer several questions regarding the health problems of children as well as parents and family psychosocial problems.

90% of the nurses answered that nursing care was very important issue in palliative care and that they should work closely with children and as well as with their families.

100% of them answered that they have experienced emotions, such as: helplessness, anger, sadness, and anxiety in palliative care children. Even, some of them had difficulties working in palliative care due to the lack of experience.

All nurses reported that palliative care in children should be learnt in comprehensive pediatric palliative care programs.



Conclusions

Nursing in palliative care in children is a crucial thing and it must be integrated with a comprehensive care including psychological and social supports to children and their families.

Recommendation

All nurses should have additional training in order to improve their abilities to communicate with patients and their families and become an integrated model with psychosocial supports.



References

1. Bomba, P.A., (2015). New York's approach to advance care planning in the pediatric population. *ChiPPS E-Journal*, (39), 5-12.
2. Bomba, P.A. Advance Care Planning Along the Health Continuum. The case Manager. 2005.
3. Bomba, P.A., & Karmel, J. B. (2015). Medical, ethical and legal obligations to honor individual preferences near the end of life. *Health Law Journal*, 20(2), 28-33.
4. Bomba, P.A., & Orem, K.G. (2015). Lessons learned from New York's community approach to advance care planning and MOLST. *Annals of Palliative Medicine*, 4(1), 10-21.
5. Bomba, PA and Orem, K. 2012. eMOLST and Electronic Health Records. *Health Law Journal* 17(2): 77-83. Published by the New York State Bar Association.
6. Karmel, J. B., & Lispon, K. (2011). Honoring patient preferences at the end of life: the MOLST process and the Family Health Care Decisions Act. *Health Law Journal*, 16(1), 36-43.
7. Bomba, P.A. Discussing Patient Preferences and End-of-Life Care. Journal of the Monroe County Medical Society, 7th District Branch, MSSNY. 2011; April 2011: 12-15.
8. Bomba, P.A., Leven, D.C., Morrissey, M.B. (2011). Key Role of Social Work in Effective Communication and Conflict Resolution Process: Medical Orders for Life-Sustaining Treatment (MOLST) Program in New York and shared Medical Decision Making at End-of-Life. *Journal of Social Work in End-of-Life & Palliative Care*, January - March 2011, Volume VII, Issue 1, 56-82.
9. Bomba, P.A. Landmark Legislation in New York Affirms Benefits of Two-Step Approach to Advance Care Planning Including MOLST: A Model of Shared, Informed Medical Decision-Making and Honoring Patient Preferences for Care at the End-of-Life. *Widener Law Review*, 2011, Volume XVII Issue 2, 475-500.
10. Grimaldi, J.D., Lawlor T.R. (2009) MOLST: New York State's Medical Orders to Honor the Wishes of a seriously ill Patient. *NYSBA Elder Law Attorney* 19:2, 15-17.
11. Bomba, P.A. Producer MOLST DVD - Informational and educational curriculum: Writing Your Final Chapter: "Know Your Choices.....Share Your Wishes" and "Honoring Patient Preferences: The Role of Medical Orders for Life-Sustaining Treatment (MOLST) in New York State."
12. Fairbanks, R.J., Shah, M.N., Lerner, E.B., Ilangovan, K., Pennington, E.C., Schneider, S.M. (2007) Epidemiology and Outcomes of out-of-hospital cardiac arrest in Rochester, New York. *Resuscitation*. 72, 415-424.
13. Bomba, P.A., Vermilyea, D. (2006) Integrating POLST Into Palliative Care Guidelines: A Paradigm Shift in Advance Care Planning in Oncology. *Journal of the National Comprehensive Cancer Network* 4:8, 819-829.



14. Bomba, P.A. (2006) Medical Orders for Life-Sustaining Treatment (MOLST): A Paradigm Shift in Advance Care Planning. *Health Law Journal*, 2006; 11:3, 39-51.
15. Bomba, P.A., Caprio, T.V., Gillespie, S.M., Richardson, K. Community Implementation of the Medical Orders for Life-Sustaining Treatment (MOLST) to Improve Advance Care Directives. *Journal of the American Geriatrics Society*. 55(1) S44.
16. Olden A., Quill T., Ladwig, S. End-of-life Care and MOLST Completion. *Journal of the American Geriatrics Society*. 55(1) S159.
17. Bomba, P.A. Enabling the transition to hospice care through effective palliative care. *The Case Manager*. 2005; 16:48 - 52.
18. Bomba, P.A., Kemp, M. and Black, J.S. POLST: An improvement over traditional advance directives. *Cleveland Clinic Journal of Medicine*. July 2012, Vol. 79, Issue 7, p. 457-64.
19. Hickman, S.E., Nelson, C.A., Moss, A.H., Tolle, S.W., Perrin, N.A. and Hammes, B.J. The Consistency Between Treatments Provided to Nursing Facility Residents and Orders on the Physician Orders for Life-Sustaining Treatment Form. *Journal of the American Geriatrics Society*. November 2011, Volume 59, Issue 11, p. 2091-99.
20. Sabatino, C.P., Karp, N. Improving Advanced Illness Care: The Evolution of State POLST Programs. AARP Public Policy Institute. Copyright 2011, AARP.
21. Bomba, P.A., Sabatino, C.P. POLST: An Emerging Model for End-of-Life Care Planning. *The Elder Law Report*. February 2009, Volume XX, Number 7, 1-5.
22. Hickman, E.S., Sabatino, C.P., Moss, A.H., Wehrle Nester, J. (Spring 2008). The POLST (Physicians Orders for Life-Sustaining Treatment) Paradigm to Improve End-of-Life Care: Potential State Legal Barriers to Implementation. *Journal of Law, Medicine & Ethics* Spring 2008, 119 - 140.
23. Bomba, P.A., Vermilyea, D. Integrating POLST into Palliative Care Guidelines: A Paradigm Shift in Advance Care Planning in Oncology. *Journal of the National Comprehensive Cancer Network*. 2006; 4:8, 819-829.
24. <https://www.compassionandsupport.org/pdfs/about/Rochester%20Community%20End%20of%20life%20Report%20012901.pdf>