THE CURRENT STATUS OF PEDIATRIC PALLIATIVE CARE IN TURKEY

Chapter

9

Metehan YANA¹

The World Health Organization (WHO) defines palliative care as "a methodology that enhances the quality of life of patients and their relatives facing the problem related with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO, 2012). Paediatric palliative care is another approach in palliative medicine which is based on similar principles of adult palliative care programs. According to the WHO (2014), 63 children (under 15 years old) out of 100,000 populations need palliative care at the end of life and approximately 1.2 million children (%52 male, %48 female) need palliative care at the end of their lives in all over the world (WHO, 2014). Children, who need palliative care at the end of life, are commonly diagnosed with congenital anomalies, neonatal conditions, meningitis, protein energy malnutrition, cardiovascular diseases and HIV/AIDS (ibid). Holistic approach of paediatric palliative and end of care includes the active care of the child's body, spirit and mind, and also includes giving support to the relatives (WHO, 2014). The crucial component of paediatric palliative care is defined by World Palliative Care Alliance; 1) palliative care begins when the children or young adult diagnosed with life threatening illness, 2) palliative care provider should be aware of child's physical, psychological, and social distress which is caused by disease and they help them to deal with these problems, 3) palliative care services might be provided in community health centres, in tertiary care facilities, and even in children's homes (WHO, 2014). Effective paediatric palliative care includes a multidisciplinary team work (e.g. practitioners, nurses, physiotherapists, social workers, etc.). Members of this team should assess and relieve a child's physical, psychological, and social distress (ibid). In this context, Physiotherapists have important place to evaluate and cope with physical challenges in palliative care at end of the life. However, there is no specific policy or document which is described role of physiotherapists in paediatric palliative care in many countries.

Lecturer, M.Sc. PT, Division of Physiotherapy and Rehabilitation, Faculty of Health Science, Karabuk University, Karabuk, Turkey metehanyana@karabuk.edu.tr

References

- 1. ARMSTRONG-DAILEY, A. & ZARBOCK, S. F. 2009. *Hospice care for children*, United States of America, Oxford University Press.
- BLUEBOND-LANGNER, M., BEECHAM, E., CANDY, B., LANGNER, R. & JONES, L. 2013. Preferred place of death for children and young people with life-limiting and life-threatening conditions: A systematic review of the literature and recommendations for future inquiry and policy. *Palliative Medicine*, 27, 705-713.
- 3. BRENNAN, F. 2007. Palliative Care as an International Human Right. *Journal of Pain and Symptom Management*, 33, 494-499.
- 4. DAVIES, B., SEHRING, S. A., PARTRIDGE, J. C., COOPER, B. A., HUGHES, A., PHILP, J. C., AMIDI-NOURI, A. & KRAMER, R. F. 2008. Barriers to Palliative Care for Children: Perceptions of Pediatric Health Care Providers. *Pediatrics*, 121, 282-288.
- 5. DEMIRBAG, B. C., KURTUNCU, M. & GUVEN, H. 2013. Knowledge of Turkish mothers with children in the 0-13 age group about cancer symptoms. *Asian Pac J Cancer Prev*, 14, 1031-5.
- 6. ELCIGIL, A. 2011. The Current Status of Palliative Care in Turkey: A Nurse's Perspective. *Journal of Pediatric Hematology/Oncology*, 33.
- 7. ELLERSHAW, J. E. & GARRARD, E. 2004. Ethical issues in palliative care. *Medicine*, 32, 27-28.
- 8. EYIGOR, S. 2013. Fifth-Year Medical Students' Knowledge of Palliative Care and Their Views on the Subject. http://dx.doi.org/10.1089/jpm.2012.0627.
- 9. FRASER, L. K., MILLER, M., HAIN, R., NORMAN, P., ALDRIDGE, J., MCKINNEY, P. A. & PARSLOW, R. C. 2012. Rising National Prevalence of Life-Limiting Conditions in Children in England. *Pediatrics*, 129, e923-e929.
- 10. GAMLIN, R. 2001. Ethical issues in palliative care. *International Journal of Palliative Nursing*, **7**, 360-360.
- 11. GOLDMAN, A., HAIN, R. & LIBEN, S. 2012. Oxford textbook of palliative care for children, Oxford University Press.
- 12. HIMELSTEIN, B. P., HILDEN, J. M., BOLDT, A. M. & WEISSMAN, D. 2004. Pediatric Palliative Care. *New England Journal of Medicine*, 350, 1752-1762.
- 13. KEBUDI, R. 2012. Pediatric Oncology in Turkey. *Journal of Pediatric Hematology/Oncology*, 34.
- 14. KINLAW, K. 2005. Ethical issues in palliative care. *Seminars in Oncology Nursing*, 21, 63-68.
- 15. KNAPP, C., WOODWORTH, L., WRIGHT, M., DOWNING, J., DRAKE, R., FOWL-ER-KERRY, S., HAIN, R. & MARSTON, J. 2011. Pediatric palliative care provision around the world: A systematic review. *Pediatric Blood & Cancer*, 57, 361-368.
- 16. KOMURCU, S. 2011. Current Status of Palliative Care in Turkey. *Journal of Pediatric Hematology/Oncology*, 33.
- 17. KUMAR, S. P. & JIM, A. 2010. Physical Therapy in Palliative Care: From Symptom Control to Quality of Life: A Critical Review. *Indian J Palliat Care*.
- 18. LAAKSO, L. 2006. The role of physiotherapy in palliative care. *Australian family physician*, 35, 781.
- 19. MICHEL, T. H. 2001. Editorial Do physiotherapists have a role in palliative care? *Physiotherapy Research International*, 6, v-vi.

- NORTHOUSE, L., WILLIAMS, A.-L., GIVEN, B. & MCCORKLE, R. 2012. Psychosocial Care for Family Caregivers of Patients With Cancer. *Journal of Clinical Oncology*, 30, 1227-1234.
- 21. OZGUL, N., GULTEKIN, M., KOC, O., GOKSEL, F., BAYRAKTAR, G., EKINCI, H., SENCAN, I., TUNCER, A. M., AKSOY, M. & TOSUN, N. 2012. Turkish community-based palliative care model: a unique design. *Ann Oncol*, 23 Suppl 3, 76-8.
- 22. OZGUL, N., KOC, O., GULTEKIN, M., GOKSEL, F., KERMAN, S., TANYERI, P., EKINCI, H., TUNCER, M. A. & SENCAN, I. 2011. Opioids for Cancer Pain: Availability, Accessibility, and Regulatory Barriers in Turkey and Pallia-Turk Project. *Journal of Pediatric Hematology/Oncology*, 33.
- 23. PASACRETA, J. V. & PICKETT, M. 1998. Psychosocial aspects of palliative care. Seminars in Oncology Nursing, 14, 110-120.
- 24. SIDEN, H., CHAVOSHI, N., HARVEY, B., PARKER, A. & MILLER, T. 2014. Characteristics of a Pediatric Hospice Palliative Care Program Over 15 Years. *Pediatrics*, 134, e765-e772.
- 25. SILBERMANN, M., ARNAOUT, M., RAHMAN SAYED, H., SEDKY, M., EL-SHAMI, M., BEN-ARUSH, M., AL-HADAD, S., HUIJER, H.-S., PITSILLIDES, B., TACYILDIZ, N., SHAD, A., RIZKALLAH, R. & ASHRAF, S. 2012. Pediatric Palliative Care in the Middle East. *In:* KNAPP, C., MADDEN, V. & FOWLER-KERRY, S. (eds.) *Pediatric Palliative Care: Global Perspectives.* Springer Netherlands.
- 26. SIMON, C. 2008. Ethical Issues in Palliative Care. *InnovAiT: The RCGP Journal for Associates in Training*, 1, 274-279.
- 27. SINGER, P. & BOWMAN, K. 2002. Quality end-of-life care: A global perspective. *BMC Palliative Care*, 1, 4.
- 28. SOURKES, B. M. 2007. Armfuls of Time: The Psychological Experience of the Child with a Life-Threatening Illness. *Medical Principles and Practice*, 16(suppl 1), 37-41.
- 29. STJERNSWÄRD, J., FOLEY, K. M. & FERRIS, F. D. 2007a. Integrating Palliative Care into National Policies. *Journal of Pain and Symptom Management*, 33, 514-520.
- 30. STJERNSWÄRD, J., FOLEY, K. M. & FERRIS, F. D. 2007b. The Public Health Strategy for Palliative Care. *Journal of Pain and Symptom Management*, 33, 486-493.
- 31. VACHON, M. L. S., KRISTJANSON, L. & HIGGINSON, I. 1995. Psychosocial issues in palliative care: The patient, the family, and the process and outcome of care. *Journal of Pain and Symptom Management*, 10, 142-150.
- 32. WHO 1996. Cancer pain relief: with a guide to opioid availability. second edition ed. GENEVA, SWITHZERLAND: World Health Organization.
- 33. WHO. 2012. WHO | WHO Definition of Palliative Care [Online]. World Health Organization. Available: http://www.who.int/cancer/palliative/definition/en/.
- 34. WHO. 2014. WHO | Global atlas of palliative care at the end of life [Online]. World Health Organization. Available: http://www.who.int/cancer/publications/palliative-care-atlas/en/ [Accessed 28/12 2014].