

## Bölüm 8

# ÇOCUKLARDA PALYATİF BAKIM VE HEMŞİRENİN ROLÜ

Tülay KUZLU AYYILDIZ<sup>1</sup>  
Musa ÖZSAVRAN<sup>2</sup>  
Aylin KURT<sup>3</sup>

### GİRİŞ

Palyatif bakım “meydana gelecek acıyı tahmin ederek, önleyerek ve tedavi ederek yaşam kalitesini optimize eden hasta ve aile merkezli bir bakım” olarak tanımlanmaktadır (Ferrell & ark, 2018; National Hospice and Palliative Care Organization, 2018). Palyatif bakım, hastalık süresince fiziksel, entelektüel, duygusal, sosyal ve manevi gereksinimlere yönelik hizmet sağlamayı hedeflemektedir ve aynı zamanda hastanın özerkliğini, bilgiye erişimi ve seçimi kolaylaştırmaktadır (Ferrell & ark, 2018; American Academy of Pediatrics, 2013).

Palyatif bakım, hasta ve ailesine destek sağlamak için doktor, hemşire, sosyal hizmet uzmanı, din görevlisi ve diğer disiplinlerden oluşan bir ekip tarafından sağlanması gereken bir hizmettir (Ferrell & ark, 2018; Friebert & Williams, 2015; National Hospice and Palliative Care Organization, 2018). Çünkü hem hastanın ve hem de ailesinin önemli boyutta yıkıcı ve yıpratıcı etkilere neden olan bir sürecin içerisinde geçmesine neden olmaktadır. Kişilerin bu süreçten en az zarar ile çıkmasına yardım etmek aslında palyatif bakım felsefesinin temelinde yer almaktadır (National Hospice and Palliative Care Organization, 2018).

<sup>1</sup> Zonguldak Bülent Ecevit Üniversitesi Sağlık Bölümleri Fakültesi, Hemşirelik Bölümü, tayyildiz67@hotmail.com

<sup>2</sup> Zonguldak Bülent Ecevit Üniversitesi, Ahmet Erdoğan Sağlık Meslek Yüksekokulu, Çocuk Bakımı ve Gençlik Hizmetleri Bölümü, musaозsавran@yandex.com

<sup>3</sup> Zonguldak Bülent Ecevit Üniversitesi Sağlık Bölümleri Fakültesi, Hemşirelik Bölümü, aylinkurt67@gmail.com

- Anksiyete
- Uyku örüntüsünde rahatsızlık
- Bakım verici rolünde zorlanma
- Spritüel Distres (Manevi Sıkıntı)
- Yorgunluk
- Güçsüzlük

## KAYNAKÇA

- Aiello-Laws, L., Reynolds, J., Deizer, N. (2009). Putting evidence into practice: What are the pharmacologic interventions for nociceptive and neuropathic cancer pain in adults? *Clinical Journal of Oncology Nursing*, 13(6), 649-655.
- Akgün Kostak, M., & Akan M. (2011) Terminal dönemdeki çocuğun palyatif bakımı. *Türk Onkoloji Dergisi*, 26(4), 182-192.
- Alnajjar H, & Elarousy W. (2017). Exploring family needs in neonatal and pediatric intensive care units at King Khaled Hospital-Jeddah. *Clini Med Invest* 2(4), 1-7.
- Altıntaş, M.E. (2018). Hastanelerde gerçekleştirilen manevi danışmanlık ve rehberlik hizmetleri üzerine nitel bir araştırma (Kayseri örneği). *Amasya Üniversitesi İlahiyat Fakültesi Dergisi*, 11(Aralık 2018), 221-256.
- American Academy of Pediatrics. (2013). Pediatric palliative care and hospice care commitments, guidelines, and recommendations. *Pediatrics*, 132(5), 966-972.
- American Academy of Pediatrics. (2000). Committee on bioethics and committee on hospital care. Palliative care for children. *Pediatrics*, 106(2 Pt 1), 351-7.
- Baenziger, P., & Moody, K. (2018). Palliative care for children with central nervous system malignancies. *Bioengineering*, 5(4), 85-88.
- Bayrakcı, B., Kesici, S., Kendirli, T., Kalkan, G., Sarı, A., Tokmak, N., ... Şencan, İ. Evaluation report of pediatric intensive care units in Turkey. *Turkish Journal of Medical Sciences*, 2014; 44, 1073-86.
- Bulut, G., Uslu, F.R., Eyigör, C., ve ark. (2017). Palyatif bakımda semptom yönetimi. (dispne, yorgunluk, bulantı-kusma, ağrı). *Türkiye Klinikleri J Anest Reanim-Special Topics*. 10(1), 25-35.
- Jacknow, D.S., Tschann, J.M., Link, M.P., et al. (1994). Hypnosis in the prevention of chemotherapy-related nausea and vomiting in children: A prospective study. *J. Dev. Behav. Pediatr.* 15, 258-264.
- Carr, D., Goudas, L., Lawrence, D., et al. (2002). Management of cancer symptoms: pain, depression, and fatigue. Evidence report/technology assessment. 61, 368-374.
- Cohen, E., Kuo, D.Z., Agrawal, R., Berry, J.G., et al. (2011). Children with medical complexity: An emerging population for clinical and research initiatives. *Pediatrics*, 127(3), 529-538.
- Children's Oncology Group (2015). Guideline for the prevention of nausea and vomiting due to antineoplastic medication in pediatric cancer patients. version september 2015. 17/07/2019 tarihinde [https://childrensoncologygroup.org/downloads/COG\\_SC\\_CINV\\_Guideline\\_Document.pdf](https://childrensoncologygroup.org/downloads/COG_SC_CINV_Guideline_Document.pdf) adresinden ulaşılmıştır.
- Çakır FB. (2018). Türkiye'de pediatrik palyatif bakım. In *Uluslararası Katılımlı Palyatif Bakım ve Hospis Kongresi*, 09-11 Mart, 2018, İstanbul, p. 24.
- Cataudella, D.A., & Zelcer, S. (2012). Psychological experiences of children with brain tumors at end of life: Parental perspectives. *J. Palliat. Med*, 15: 1191-1197.
- Davis, C.L. (1994). The therapeutics of dyspnoea. *Cancer Surv. Review*. 21:85-98.
- Emanuel, E.J., Fairclough, D.L., Slutsman, J., et al. (2000). Understanding economic and other burdens of terminal illness: The Experience of patients and their caregivers. *Ann Intern Med*. 132:451-9.
- Fagen, T.S. (1982). Music therapy in the treatment of anxiety and fear in terminal pediatric patients. *Music Ther.* 2, 13-23.

- Ferrell, B.R., Twaddle, M.L., Melnick, A., et al. (2018). National consensus project clinical practice guidelines for quality palliative care guidelines, 4th edition. *Journal of Palliative Medicine*, 21(12), 1684–1689.
- Fischer, C., Petriccione, M., Donzelli, M., et al. (2016). Improving Care in Pediatric Neuro-oncology Patients: An Overview of the Unique Needs of Children with Brain Tumors. *J. Child Neurol.* 31: 488–505.
- Friebert S, & Williams C. (2015). NHPCO's facts and figures pediatric palliative & hospice care in America. (16/06/2019 tarihinde [https://www.medschool.lsuhscc.edu/medical\\_education/Undergraduate/clerkships/\(1\)%20NHPCO%20PPHC%20Facts%20and%20Figures.pdf](https://www.medschool.lsuhscc.edu/medical_education/Undergraduate/clerkships/(1)%20NHPCO%20PPHC%20Facts%20and%20Figures.pdf) adresinden ulaşılmıştır)
- Gagnon, P.R. (2008). Treatment of delirium in supportive and palliative care. *Current Opinion in Supportive and Palliative Care.* 2, 60-6.
- Geneva: World Health Organization (1998). WHO definition of palliative care. (16/06/2019 tarihinde <https://www.who.int/cancer/palliative/definition/en/> adresinden ulaşılmıştır)
- Gundo, R., Bodole, F., Lengu, E., et al. (2014). Comparison of nurses' and families' perception of family needs in critical care unit at referral hospitals in Malawi. *Open Journal of Nursing*, 4, 312–320.
- Günay, O., Sevinç, N., & Aslantaş, E.E. (2017). Hastanede yatan çocukların annelerinde durumluk ve sürekli anksiyete düzeyi ve ilişkili faktörler. *Turk J Public Health*, 15(3), 176–186.
- Grassi, L., Caraceni, A., Mitchell, A.J., et al. (2015). Management of delirium in palliative care: A review. *Current Psychiatry Reports*, 17, 13-18.
- Herr, K., Coyne, P.J., Manworren, R., et al. (2006). Pain assessment in the non-verbal patient: Position statement with clinical practice recommendations. *Pain Management Nursing*, 7(2), 44-52.
- Hosker, C.M., Bennett, M.I. (2016). Delirium and agitation at the end of life. *BMJ.* 353:i3085.
- Huhmann, M.B., August, D.A. (2008). Review of american society for parenteral and enteral nutrition (ASPEN) Clinical guidelines for nutrition support in cancer patients: nutrition screening and assessment. *Nutr Clin Pract.* 23(2), 182-8.
- Johnston, B., Jindal-Snape, D., Pringle, J. (2016). Life transitions of adolescents and young adults with life-limiting conditions. *Int. J. Palliat. Nurs.* 22, 608–617.
- Kabalak, A.A., Öztürk, H., & Çağıl, H. (2013). Yaşam sonu bakım organizasyonu; palyatif bakım. *Yoğun Bakım Dergisi*, 11(2), 56-70.
- Kang, T., Hoehn, S., Licht, D.J., et al. (2005). Pediatric palliative, end-of-life, and bereavement care. *Pediatric Clinical of North America*, 52, 1029-1046.
- Kenny, N.P., Frager, G. (1996). Refractory symptoms and terminal sedation of children: Ethical issues and practical management. *J. Palliat. Care.* 12, 40–45.
- Komatz, K., Carter, B. (2015). Pain and symptom management in pediatric palliative care. *Pediatr. Rev.* 36, 527-534.
- Kroenke, K., Theobald, D., Wu, J., et al. (2010). The association of depression and pain with health-related quality of life, disability, and health care use in cancer patients. *J Pain Symptom Manage.* 40, 327-41.
- Lalic, N., Lalic, I., Tomic, S., Dolinaj, V., & Lecic, S.K. (2018). Spiritual support as a part of palliative care of lung cancer patients. *Medicinski Pregled*, 71(S1), 37-43.
- Lan, K.G., & Yun, L.W. (2015). Parents' perspectives on the important aspects of care in children dying from life limiting conditions: A qualitative study. *Medical Journal of Malaysia*, 70(5), 295–299.
- Levine, D.R., Mandrell, B.N., Sykes, A., et al. (2017). Patients' and parents' needs, attitudes, and perceptions about early palliative care integration in pediatric oncology. *JAMA Oncology*, 3(9), 1214–1220.
- Madenoglu Kivanç, M. (2017). Türkiye'de palyatif bakım hizmetleri. *Sağlık Bilimleri ve Meslekleri Dergisi*, 4(2), 141–141.
- Major, P., Greenberg, E., Khan, A., et al. (2008). Pyridoxine supplementation for the treatment of levetiracetam-induced behavior side effects in children: Preliminary results. *Epilepsy Behav.* 13, 557–559.

- Manworren, R.C., Hyman, L.S. (2003). Clinical validation of FLACC: Preverbal patient pain scale. *Pediatr Nurs.* 29, 140–146.
- Marston, J. (2015). A global history of children's palliative care. 30/06/2019 tarihinde <http://www.icpcn.org/a-global-history-of-childrens-palliative-care/adresinden-ulaşilmiştir>
- Michelle, N. (2011). Addressing children's beliefs through fowler's stages of faith. *J. Pediatr. Nurs.* 26, 44–50.
- Michelson, K.N., & Steinhorn, D.M. (2007). Pediatric end-of-life issues and palliative care. *Clin Pediatr Emerg Med*, 8(3), 212–219.
- Mullen, J.E., Reynolds, M.R., & Larson, J.S. (2015). Caring for pediatric patients' families at the child's end of life. *Crit Care Nurse*, 35(6), 46–56.
- National Hospice and Palliative Care Organization. (2018). Facts and figures hospice care in America: 2017 edition, 1–11.
- Olagunju, A.T., Sarimiye, F.O., Olagunju, T.O., et al. (2016). Child's symptom burden and depressive symptoms among caregivers of children with cancers: an argument for early integration of pediatric palliative care. *Ann Palliat Med*, 5(3), 157–165.
- Özkan, A. (2017). Hastanelerde sunulan manevi danışmanlık ve rehberlik hizmetleri üzerine bir araştırma. A. Ayten (Editör), *Manevi Danışmanlık ve Rehberlikinde* (ss. 62). İstanbul: DEM Yayınları.
- Özkan, S. (2011). Kronik obstrüktif akciğer hastalığı'nda (KOA) palyatif ve yaşam sonu bakımı. *Selçuk Tıp Derg.* 28(1), 69-74.
- Puchalski, C., Ferrell, B., Virani, R., et al. (2009). Improving the quality of spiritual care as a dimension of palliative care: The Report of the consensus conference. *J. Palliat. Med.* 12, 885–904.
- Rabow, M.W., Pantilat, S.Z. (2005). Care at the end of life. In: Tierney LM, McPhee SJ, Papadakis MA (eds). *Current Medical Diagnosis and Treatment*. 44th edition (65-84). NewYork: McGraw-Hill
- Ready, T. (2010). Music as language. *Am. J. Hospice Palliat. Med.* 27, 7-15.
- Roy, D.J. (1996). On the ethics of euthanasia discourse. *J. Palliat. Care.* 12, 3–5.
- Santucci, G., Mack, J.W. (2007). Common gastrointestinal symptoms in pediatric palliative care: Nausea, vomiting, constipation, anorexia, cachexia. *Pediatric Clinics of North America.* 54(5), 673-689.
- Spruit, J.L., & Prince-Paul, M. (2018). Palliative care services in pediatric oncology. *Ann Palliat Med*, 8(Suppl 1), S49–S57.
- Stewart, G., McNeilly, P. (2011). Opioid-induced constipation in children's palliative care. *NursChild Young People.* 23(8),31-4.
- Stayer, D, & Lockhart, J.S. (2016). Living with dying in the pediatric intensive care unit: A nursing perspective. *Am J Crit Care*, 25(4), 350–6.
- Theunissen, J.M., Hoogerbrugge, P.M., van Achterberg, T., et al. (2007). Symptoms in the palliative phase of children with cancer. *Pediatr Blood Cancer.* 49,160-165.
- Tsao, J.C., Meldrum, M., Kim, S.C., et al. (2007). Treatment Preferences for CAM in children with chronic pain. *Evid. Based Complement. Alternat. Med.* 4,367–374.
- Tsao, J.C., Zeltzer, L.K. (2005). Complementary and alternative medicine approaches for pediatric pain: A review of the state-of-the-science. *Evid. Based Complement. Alternat. Med.* 2,149–159.
- Uysal, V., Göktepe, A.K, Karagöz, S., ve ark. (2017). Dini başa çıkma ile umut, hayat memnuniyeti ve psikolojik sağlamlık arasındaki etkileşim üzerine bir araştırma. *Marmara Üniversitesi İlahiyat Fakültesi Dergisi*, 52, 139–160.
- Verberne, L.M., Schouten-van Meeteren, A.Y.N., Bosman, D.K., et al. (2017). Parental experiences with a paediatric palliative care team: A qualitative study. *Palliative Medicine*, 31(10), 956–963.
- Vgontzas, A.N., Chrousos, G.P. (2002). Sleep, the hypothalamicpituitary- adrenal axis, and cytokines: multiple interactions and disturbances in sleep disorders. *Endocrinol Metab Clin North Am.* 31(1),15-36.
- Vickers, A.J. (1996). Can acupuncture have specific effects on health? A systematic review of acupuncture antiemesis trials. *J. R. Soc. Med.* 6, 303-311.
- Von Roenn, J.H. & Paice, J.A. (2005). Control of common, non-pain cancer symptoms. *Semin Oncol.* 32,200-10.

- Weerakkody, I., Hales, S., Fernandes, S., et al. (2018). The quality of dying and death in a residential hospice. *Journal of Pain and Symptom Management*, 56(4), 567–574.
- Wigert, H., Bry, K. (2018). Dealing with parents' existential issues in neonatal intensive care. *Journal of Neonatal Nursing*, 24(4), 213–217.
- Wusthoff, C.J., Shellhaas, R.A., & Licht, D.J. (2007). Management of common neurologic symptoms in pediatric palliative care: Seizures, agitation, and spasticity. *Pediatric Clinics of North America*. 54(5): 709-733.
- Yeloğlu ÇH, Güveli H, Hocaoğlu Ç (2015). Son Dönem Hastalarında Psikiyatrik Yaklaşım 20/07/2019 tarihinde [https://www.researchgate.net/profile/Cicek\\_Hocaoglu3/publication/277774436\\_Psychiatric\\_Approach\\_in\\_Terminally\\_Ill\\_Patients/links/55db596d08aec156b9afe8da/Psychiatric-Approach-in-Terminally-Ill-Patients.pdf](https://www.researchgate.net/profile/Cicek_Hocaoglu3/publication/277774436_Psychiatric_Approach_in_Terminally_Ill_Patients/links/55db596d08aec156b9afe8da/Psychiatric-Approach-in-Terminally-Ill-Patients.pdf) adresinden ulaşılmıştır.)