DERLEME/REVIEW
Journal of Advanced Research in Health Sciences /
Sağlık Bilimlerinde İleri Araştırmalar Dergisi 2023
DOI: 10.26650/JARHS2023-1214456

ADVANCE CARE PLANNING IN ADULT AND PEDIATRIC CANCER PATIENTS: A REVIEW

YETİŞKİN VE PEDİATRİK KANSERLİ HASTALARDA İLERİ BAKIM PLANLAMASI: GÖZDEN GEÇİRME

Yağmur BERKTAŞ[1], Ülkü Miray YILDIRIM[2], Rejin KEBUDİ[2]

[1]Istanbul University, Institute of Graduate Studies in Health Sciences, Supportive Treatment and Care in Cancer Patients, Istanbul, Turkiye
[2] Istanbul University, Institute of Oncology, Department of Preventive Oncology, Istanbul, Turkiye

ORCID ID: Y.B. 0000-0002-2221-3029; Ü.M.Y. 0000-0003-0585-5123; R.K. 0000-0003-4343-8174

Citation/Atıf: Berktas Y, Yildirim UM, Kebudi R. Advance care planning in adult and pediatric cancer patients: a review. Journal of Advanced Research in Health Sciences 2023;6(2):192-196. https://doi.org/10.26650/JARHS2023-1214456

ABSTRACT

Advance care planning (ACP) aims to support patients regardless of age or stage of health to understand and share personal values, goals in life, and future medical care preferences. This process which may be started at any time should be reviewed at periodical intervals depending on individuals' medical conditions. According to previous research, end-of-life care is a source of deep concern for many people who want to ensure active involvement in decision-making processes. Compared to other patient groups, individuals suffering from advanced cancer may have different levels of willingness regarding being a part of ACP discussions, as evidence shows. The barriers to ACP, the fear surrounding ACP, cultural differences, and previous health experiences have generated differences of opinion on the use and implementation of ACP. Across the world, palliative care principles and advance care planning are developing in the field of Medical Oncology. This review aimed to present the most important features of ACP in adult and pediatric cancer patients and to incorporate this concept to Turkish literature.

Keywords: Advance care planning, adult cancer, pediatric cancer

ÖZ

İleri bakım planlaması (İBP) herhangi bir yaştaki veya sağlıklarının farklı aşamalarındaki yetişkinlerin kişisel değerlerini, yaşam hedeflerini ve gelecekteki tıbbi bakımla ilgili tercihlerini anlama ve paylaşma konusunda destekleyen bir süreçtir. Bu süreç herhangi bir zamanda başlayabilir ve periyodik olarak tekrar gözden geçirilebilir fakat bir kişinin tıbbi durumu her değiştiğinde İBP' ye yeniden odaklanılmalıdır. Daha önceki araştırmalar, birçok insanın yaşamlarının sonunda bakımla ilgili endişe ve isteklerinin olduğunu ve karar alma süreçlerine aktif olarak katılmak istediklerini ortaya koymuştur. İleri evre kanser tanısı olan bireylerin İBP tartışmalarına katılma istek ve arzularının diğer hasta gruplarına göre farklılık gösterdiğine dair kanıtlar mevcuttur. İBP kullanımı ve uygulanmasında hâla görüş farklılıkları bulunmaktadır. Bu görüş farklılıklarının nedenleri arasında İBP' nin önündeki engellerin, İBP'yi çevreleyen korkunun, kültürler arası farklılıkların ve önceki sağlık deneyimlerinin etkisi olabilmektedir. Dünya' da Tıbbi Onkoloji alanında, palyatif bakım ilkeleri ve ileri bakım planlaması için giderek artan bir literatür mevcuttur. Bu derlemenin amacı; Erişkin ve çocuk kanser hastalarında İBP' nin göze çarpan özelliklerini aydınlatmak ve bu kavramı Türk literatürüne kazandırmaktır.

Anahtar Kelimeler: İleri bakım planlaması, yetişkin kanser, pediatrik kanser

INTRODUCTION

Advance care planning (ACP) is designed to define patients' future medical and end-of-life care based on their values, wishes, and preferences from the beginning of their illness to the end of life (1). ACP was first defined by Joan Teno et al. As "a communication process that aims to ensure the consistency of clinical care with the care preferences of patients" (2). Parallel to this definition, a consensus stated the goal of ACP in 2017 ACP as "giving individuals the opportunity to determine their own values, to think deeply about what serious illness means and what consequences it has, to detail their goals and preferences in regards to the future medical treatment and care they would like to receive, and to discuss all options with their respective families" (3,4).

ACP addresses individuals as a whole and focuses on physical, psychological, social, and spiritual concerns. It has been shown that advance care planning improves the quality of life (5). In addition, ACP encourages individuals to select a representative for themselves and to record any preferences by regularly reviewing them (3,6). However, care personnel should have the

Corresponding Author/Sorumlu Yazar: Rejin KEBUDİ **E-mail:** rejinkebudi@yahoo.com

Submitted/Başvuru: 04.12.2022 • **Revision Requested/Revizyon Talebi:** 12.12.2022 • **Last Revision Received/Son Revizyon:** 25.02.2023 • **Accepted/Kabul:** 28.02.2023 • **Published Online/Online Yayın:** 25.04.2023

capacity to undertake the necessary steps so that ACP can provide the individuals with the opportunity to plan their future care and support, including medical treatment (7).

While not everyone in the community may be willing to make a prospective care plan, ACP will be useful for specific groups. For example, prolongation of hospitalization due to chronic diseases affects the decision-making ability of individuals by causing mood changes (7). ACP is more commonly used in Europe and America for cancer patients, in addition for patients with other serious diseases such as chronic obstructive pulmonary disease (COPD), human immunodeficiency virus (HIV), and amyotrophic lateral sclerosis (ALS) (8, 9).

Today, the concept of ACP has been expanded to include more patient groups as well as healthy individuals (3, 10). ACP is expected to reduce concerns about the future and improve patients' and their relatives' quality of life (11). Giving patients a sense of control and a peace of mind, and ensuring that patients can talk about end-of-life issues with family and friends are among the reported ACP benefits (8). Ideally, these discussions take place with the individual's health care representative and clinician along with clinical team members. These discussions should be recorded and updated when the need arises to ensure flexible decision making in regard to patient's current medical condition (12). Current guidelines recommend that specialist physicians initiate advance care planning discussions (9, 13). However, little is known about the preferences of general population about the individuals with whom they would like to discuss end-of-life care choices and with whom they can really involve in these discussions (14).

Despite the positive evidence for the effectiveness of ACP, clinical practice does not really entail such discussions between patients and healthcare professionals to take place at the desired level (15,16). This may be partly due to barriers related to patients (8, 17). For example, patients reported reluctance to take part in ACP discussions due to their fear of facing death, the worry about placing an unnecessary burden on their families, and the feeling that it would be impossible to plan for the future (18) (Table 1). It is stated that patients' lack of knowledge about ACP may cause inadequate use of ACP (19). Barriers faced by physicians include lack of knowledge in handling discussions about ACP, not knowing the appropriate time for discussion, the belief that patients should initiate the discussion, the fear of losing hope and revealing unmet needs (20). Another study cited the barriers to ACP as: 1) the perception that ACP discussions are overwhelming or stressful for the patient, 2) the wish to represent the care plan and its course positively, 3) the concern that it may create difficulties in accepting poor prognosis, and 4) the complexity surrounding patients' understanding about the complications of life-prolonging procedures (21, 22). However, the angles of the ACP discussions that were difficult and unpleasant at the beginning may later be considered beneficial. Starting ACP at very early stages can generate concern and anxiety (9). A systematic review demonstrated that the ACP process is more beneficial and positive for the patients depending on the readiness of the patient (8).

Another review presented that ACP training provided to healthcare professionals positively affected their knowledge, attitudes, and skills and increased their communication skills in discussing the decisions about end-of-life. Adequate training and experience will help doctors and nurses in addressing patients' and their families' needs and preferences regarding their care (23). It is imperative that healthcare professionals create the required time and venue for ACP in patients' social and healthcare settings to ensure active and meaningful involvement of patients (9).

Advance care planning in adult cancer patients

With the help of ACP, patients will be able to reflect on and share their personal values, life goals, and preferences regarding their prospective medical treatment and care (4). ACP reduces the burden on doctors and family members by minimizing the rate of using undesired treatments at the end of patients' lives. Although ACP is an encouraging and favorable approach to increase the quality of life in advance cancer patients, there is inadequate evidence backing its effectiveness for this patient group (11, 24). The cancer patients' responses to ACP and their values and needs have been reported to be different compared to other patient populations (9). Among the patients with advance cancer, the individuals who are close to death may be more open to early end-of-life conversations (25). On the other hand, a study conducted with cancer patients in 6 countries showed that while patients who participated in ACP discussions received specialist palliative care support more frequently, ACP discussions had no effect on their life quality, coping mechanisms or taking part in processes related to decision-making (24).

Table 1: Barriers to ACP

Factors related to patients	Factors related to health care professionals	Factors related to the system
Insufficient information about health status	Hesitations to discuss possible future complications with patients, especially when they seem well	Focusing on medical treatment in general
Unpredictable course of the disease and difficult prognosis	Fear of taking away the feeling of hope from the patient	Lack of coordinated and structured approach to ACP
Hesitation about considering/discussing treatment choices	Time barrier	Uncertainty in the literature about ACP initiation
Expectations that doctors should initiate ACP	Difficulties in finding the right moment to start ACP	Limited resources

ACP: Advance care planning

Advance care planning for pediatric cancer patients

Advance care planning is widely advocated to increase the participation of patients and family members in areas related to comprehending the values, preferences, and care goals of the patients regardless of prognosis and the course of the disease (26, 27). ACP requires a communication process that aims to timely coordinate prospective medical care and treatment with the patients' values and preferences throughout the disease (27).

Cancer diagnosis affects the individual and the family for a long time to come (28). Since the treatment process is highly complex, clinicians, parents, and children regularly encounter difficult decisions and discussions about not only the current care and treatment options, but also about the future ones as well (29). ACP is strongly recommended for children and adolescents by international guidelines and medical societies (26). However, research on pediatric ACP is highly limited, and little is known about how families respond to this concept (30). In particular, pediatric ACP lacks the professional perspective (31). The literature on ACP in the field of pediatrics primarily focuses on the intensive care setting and oncology population (32). In these populations, discussions of ACP are often driven by the imminent expectation of death, the need for explanation regarding resuscitation practices, the situations where curative treatments have failed, and where the focus is palliative care.

There are many barriers to ACP discussions such as unrealistic expectations and differences between how the parent and the clinician understand and approach the prognosis (33, 34). The clinicians reported that they were uncomfortable with ACP due to the fear of losing hope, the uncertainty of prognosis, and not knowing the right time to address these problems (33). Research has shown that many clinicians knowingly avoid these discussions not to destroy or damage patients' feelings of hope, even when the individual is in the advanced stages of the disease (35, 36). In addition, a lack of communication about living with the disease among individuals with cancer, parents, and healthcare professionals has been consistently reported by various studies (37-39). The physician must first understand the child's and family's perspective on the illness and its effect on their lives. Beliefs, values, hopes, and fears shape their perspectives and must be understood to guide them throughout the process (40).

When pediatric cancer patients are excluded from treatment discussions and decisions, they may have difficulties in coping with their disease (41). Palliative care with ACP is an evidence-based standard of care in pediatric cancer (42). The importance of communication on the application of ACP with pediatric cancer patients is indicated in several studies (29,43,44). According to studies, pediatric cancer patients and their families wish to receive direct, empathetic, and frequent communication, even when the disease is progressive (44, 45).

Children and adolescents with cancer may desire information and the ability to take part in decision making to identify their care plan, to choose and refuse treatment, and to decide how they will be remembered after their death (46, 47). Discussions related to care and ACP will ensure that patients will make sense of and course their hopes, fears, and care preferences more securely (47). Studies have shown that ACP discussions do not harm the patient in regards to anxiety (46, 48). A study conducted with children with cancer and their families compared randomly selected families for pediatric advance care planning with the families in the control group and reported that care giving was evaluated more positively and stated that ACP discussion experiences were valuable (30).

The best interests of the child should be kept in mind when considering the decisions regarding end-of-life care. ACP will support pediatricians in their efforts to engage in sensitive, timely, and honest discussions so that the wishes of families at the end of their child's life can be facilitated (49). It is important to consider the cultural differences in the society and the desires and views of the family during ACP discussions.

CONCLUSION

ACP is associated with positive outcomes and should be encouraged regardless of the limitations and critical issues surrounding the concept. Many healthcare organizations are seeking strategies to integrate ACP into their regular practices. A comprehensive approach beyond a single setting and a single discipline is necessary for ACP to be regarded as a continuous conversational process across time and settings (50). Since ACP may generate fear and distress, it appears to carry both benefits and risks, in social, psychological, and emotional realms which may affect patients, family members, and healthcare professionals in different ways. The end-of-life behaviors and choices of patients, their loved ones, and caregivers are strongly influenced by the organizational culture, as well as by their earlier experiences with the treatment setting or death. Therefore, ACP is not only about patients' choices, it is the outcome of a complicated and ever-changing reciprocity between patients and caregivers. The level of joint decision-making desired by individuals should be determined. Open and honest discussions should be initiated at the earliest opportunity. Health professionals have a duty to plan advance care so that severely ill patients can be provided with care that meets their individual needs. In this context, facilitating patient autonomy is both complicated and controversial. In Turkiye, ACP is not yet implemented in institutions due to uncertainties and legal reasons. More research is needed to raise awareness related to ACP, to present the ethical framework for ACP, and to grasp the philosophical approach of healthcare professionals, cancer patients, and caregivers towards ACP.

Peer Review: Externally peer-reviewed.

Author Contributions: Conception/Design of Study- R.K., Y.B.; Drafting Manuscript- Y.B., R.K., Ü.M.Y.; Final Approval and Accountability- Y.B., R.K., Ü.M.Y.

Conflict of Interest: The authors have no conflict of interest to declare.

Financial Disclosure: The authors declared that this study has received no financial support.

REFERENCES

1. Sedini C, Biotto M, Crespi Bel'skij LM, Moroni Grandini RE, Cesari M. Advance care planning and advance directives: an overview of the main critical issues. Aging Clin Exp Res 2022;34(2):325-30.
2. Teno JM, Nelson HL, Lynn J. Advance care planning. Priorities for ethical and empirical research. Hast Cent Rep 1994;24(6):S32-6.
3. Rietjens JAC, Sudore RL, Connolly M, van Delden JJ, Drickamer MA, Droger M, et al. European association for palliative care definition and recommendations for advance care planning: an international consensus supported by the european association for palliative care. Lancet Oncol 2017;18(9):543-51.
4. Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, et al. Defining advance care planning for adults: a consensus definition from a Multidisciplinary Delphi Panel. J Pain Symptom Manage 2017;53(5):821-32.
5. Owen L, Steel A. Advance care planning: what do patients want? Br J Hosp Med 2019;80(5):263-7.
6. Sudore RL, Boscardin J, Feuz MA, McMahan RD, Katen MT, Barnes DE. Effect of the PREPARE Website vs an Easy-to-Read Advance Directive on Advance Care Planning Documentation and Engagement Among Veterans: A Randomized Clinical Trial. JAMA 2017;177(8):1102-9.
7. National Institute for Health and Care Excellence. Advance care planning. University of Nottingham 2019- Jan (cited 2023 Jan 13): 1(1). Available from:file:///C:/Users/90506/Downloads/advance-care-planningquick-guide.pdf.
8. Zwakman M, Jabbarian LJ, van Delden J, van der Heide A, Korfage IJ, Pollock K, et al. Advance care planning: A systematic review about experiences of patients with a life-threatening or life-limiting illness. Palliative Medicine 2018;32(8):1305-21.
9. Johnson S, Butow P, Kerridge I, Tattersall M. Advance care planning for cancer patients: a systematic review of perceptions and experiences of patients, families, and healthcare providers. Psychooncology 2016;25(4):362-86.
10. Fleuren N, Depla MFIA, Janssen DJA, Huisman M, Hertogh CMPM. Underlying goals of advance care planning (ACP): a qualitative analysis of the literature. BMC Palliat Care 2020;19(1):27.
11. Brinkman-Stoppelenburg A, Rietjens JA, Van Der Heide A. The effects of advance care planning on end-of-life care: a systematic review. Palliat Med 2014;28(8):1000-25.
12. Committee on Approaching Death: Addressing Key End of Life Issues; Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Washington (DC): National Academies Press (US); March 19, 2015.p.624-6242.
13. Houben CHM, Spruit MA, Groenen MTJ, Wouters EFM, Janssen DJA. Efficacy of advance care planning: a systematic review and meta-analysis. J Am Med Dir Assoc 2014;15(7):477-89.
14. Busa C, Pozsgai E, Zeller J, Csikos A. Who should talk with patients about their end-of-life care wishes? A nationwide survey of the Hungarian population. Scand J Prim Health Care 2022;40(1):157-64.
15. Jabbarian LJ, Zwakman M, van der Heide A, Kars MC, Janssen DJA, van Delden JJ, et al. Advance care planning for patients with chronic respiratory diseases: a systematic review of preferences and practices. Thorax 2018;73(3):222-30.
16. Rietjens J, Korfage I, Taubert M. Advance care planning: the future. BMJ Support Palliat Care 2021;11(1):89-91.
17. Mullick A, Martin J, Sallnow L. An introduction to advance care planning in practice. BMJ 2013;347(3):60-4.
18. Simon J, Porterfield P, Bouchal SR, Heyland D. 'Not yet' and 'Just ask': barriers and facilitators to advance care planning – a qualitative descriptive study of the perspectives of seriously ill, older patients and their families. BMJ Support Palliat Care 2015;5(1):54-62.
19. Kermel-Schiffman I, Werner P. Knowledge regarding advance care planning: a systematic review. Arch Gerontol Geriatr 2017;73:133-42.
20. Howard M, Bernard C, Tan A, Slaven M, Klein D, Heyland DK. Advance care planning: Let's start sooner. Can Fam Physician 2015;61(8):663-5.
21. Demirkapu H, Van den Block L, De Maesschalck S, De Vleminck A, Colak FZ, Devroey D. Advance care planning among older adults of Turkish origin in Belgium: exploratory interview study. J Pain Symptom Manage 2021;62(2):252-9.
22. Spring J, McKinlay J, Puxty K, Metaxa V, Detsky M, Mehta S, et al. Perspectives on advance care planning for patients with hematologic malignancy: an international clinician questionnaire. Ann Am Thorac Soc 2021;18(9):1533-9.
23. Chan CWH, Ng NHY, Chan HYL, Wong MMH, Chow KM. A systematic review of the effects of advance care planning facilitators training programs. BMC Health Serv Res 2019;19(1):362.
24. Korfage IJ, Carreras G, Arnfeldt Christensen CM, Billekens P, Bramley L, Briggs L, et al. Advance care planning in patients with advanced cancer: A 6-country, cluster-randomised clinical trial. PLoS Med 2020;17(11):e1003422
25. Resick JM, Arnold RM, Sudore RL, Farrell D, Belin S, Althouse AD, et al. Patient-centered and efficacious advance care planning in cancer: Protocol and key design considerations for the PEACe-compare trial. Contemp Clin Trials 2020;96(12):106-71
26. American Academy of Pediatrics. Committee on Bioethics and Committee on Hospital Care. Palliative care for children. Pediatrics 2000;106(5):351-3.
27. van Driessche A, Gilissen J, De Vleminck A, Kars M, Fahner J, van der Werff Ten Bosch J, et al. The BOOST paediatric advance care planning intervention for adolescents with cancer and their parents: development, acceptability and feasibility. BMC Pediatr 2022;22(1):210.
28. Holland LR, Walker R, Henney R, Cashion CE, Bradford NK. Adolescents and Young Adults with Cancer: Barriers in Access to Psychosocial Support. J Adolesc Young Adult Oncol 2021;10(1):46-55.
29. Pinkerton R, Donovan L, Herbert A. Palliative care in adolescents and young adults with cancer-why do adolescents need special attention? Cancer J 2018;24(6):336-41.
30. Thompkins JD, Needle J, Baker JN, Briggs L, Cheng YI, Wang J, et al. Pediatric advance care planning and families' positive caregiving appraisals: An RCT. Pediatrics 2021;147(6):e2020029330. doi:10.1542/peds.2020-029330
31. Lotz JD, Jox RJ, Borasio GD, Führer M. Pediatric advance care planning from the perspective of health care professionals: a qualitative interview study. Palliat Med 2015;29(3):212-22.

32. Orkin J, Beaune L, Moore C, Weiser N, Arje D, Rapoport A, et al. Toward an understanding of advance care planning in children with medical complexity. Pediatrics 2020;145(3):e20192241.
33. Friedman SL. Parent resuscitation preferences for young people with severe developmental disabilities. J Am Med Dir Assoc 2006;7(2):67-72.
34. Bogetz JF, Bogetz AL, Gabhart JM, Bergman DA, Blankenburg RL, Rassbach CE. Continuing education needs of pediatricians across diverse specialties caring for children with medical complexity. Clinical Pediatrics 2015;54(3):222-27.
35. Almack, K, Cox, K, Moghaddam, N, Pollock K, Seymour J. After you: Conversations between patients and healthcare professionals in planning for end of life care. BMC Palliat Care 2012;11:15.
36. Abernethy, ER, Campbell, GP and Pentz, RD. Why many oncologists fail to share accurate prognoses: They care deeply for their patients. Cancer 2020;126(6):1163-5.
37. Lotz JD, Daxer M, Jox RJ, Borasio GD, Führer M. "Hope for the best, prepare for the worst": A qualitative interview study on parents' needs and fears in pediatric advance care planning. Palliat Med 2017;31(8):764-71.
38. Christenson K, Lybrand SA, Hubbard CR, Hubble RA, Ahsens L, Black P. Including the perspective of the adolescent in palliative care preferences. J Pediatr Heal Care 2010;24(5):286-91.
39. Belpame N, Kars MC, Beeckman D, Decoene E, Quaghebeur M, Van Hecke A, et al. "the AYA director": A synthesizing concept to understand psychosocial experiences of adolescents and young adults with cancer. Cancer Nurs 2016;39(4):292-302.
40. Baker JN, Hinds PS, Spunt SL, Barfield RC, Allen C, Powell BC, et al. Integration of palliative care practices into the ongoing care of children with cancer: individualized care planning and coordination. Pediatr Clin North Am 2008;55(1):223-50.
41. Wiener L, Bedoya S, Battles H, Sender L, Zabokrtsky K, Donovan KA, et al. Voicing their choices: Advance care planning with adolescents and young adults with cancer and other serious conditions. Palliat Support Care 2022;20(4):462-70.
42. Weaver MS, Heinze KE, Kelly KP, Wiener L, Casey RL, Bell CJ, et al. Palliative care as a standard of care in pediatric oncology. Pediatr Blood Cancer 2015;62(5):829-33.
43. Kassam A, Skiadaresis J, Habib S, Alexander S, Wolfe J. Moving toward quality palliative cancer care: Parent and clinician perspectives on gaps between what matters and what is accessible. J Clin Oncol 2013;31(7):910-15.
44. Kaye EC, Woods C, Kennedy K, Velrajan S, Gattas M, Bilbeisi T, et al. Communication around palliative care principles and advance care planning between oncologists, children with advancing cancer and families. Br J Cancer 2021;125(8):1089-99.
45. Mack JW, Fasciano KM, Block SD. Communication about prognosis with adolescent and young adult patients with cancer: information needs, prognostic awareness, and outcomes of disclosure. J Clin Oncol 2018;36(18):1861-7.
46. Wiener L, Zadeh S, Battles H, Baird K, Ballard E, Osherow J, et al. Allowing adolescents and young adults to plan their end-of-life care. Pediatrics 2012;130(5):897-905.
47. Weaver MS, Wiener L, Jacobs S, Bell CJ, Madrigal V, Mooney-Doyle K, et al. Weaver et al's Response to Morrison: Advance Directives/Care Planning: Clear, Simple, and Wrong. J Palliat Med 2021;24(1):8-10.
48. Fladeboe KM, O'Donnell MB, Barton KS, Bradford MC, Steineck A, Junkins CC, et al. A novel combined resilience and advance care planning intervention for adolescents and young adults with advanced cancer: A feasibility and acceptability cohort study. Cancer 2021;127(23):4504-11.
49. Heckford E, Beringer, A. Advance care planning: challenges and approaches for pediatricians. J Palliat Med 2015;17(9):1049-53.
50. Izumi S. Advance care planning: the nurse's role. Am J Nurs 2017;117(6):56-61.