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

YETİŞKİN VE PEDİATRİK KANSERLİ HASTALARDA İLERİ BAKIM PLANLAMASI: GÖZDEN GEÇİRME

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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

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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.

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