

Demands and needs of adolescents and young adults under oncological treatment

Demandas e necessidades de adolescentes e adultos jovens em tratamento oncológico

Demandas y necesidades de los adolescentes y adultos jóvenes en tratamiento oncológico

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Resumo

Objetivo: Descrever as evidências científicas no tocante às demandas e às necessidades de adolescentes e adultos jovens em tratamento oncológico.

Métodos: Revisão integrativa da literatura cuja estratégia de busca foi aplicada nas bases PubMed®, *The Cochrane Library* e Biblioteca Virtual em Saúde. Os critérios de inclusão foram: artigos disponíveis na íntegra on-line relacionados às demandas e às necessidades de adolescentes e/ou adultos jovens durante o tratamento oncológico em inglês, português e espanhol publicados entre 1º de janeiro de 2010 a 31 de agosto de 2020.

Resultados: Obtiveram-se 1.397 artigos. Pela leitura de seus títulos e resumos, foram excluídos 1.332. Do restante, 2 não foram encontrados na íntegra e 40 foram excluídos após leitura na íntegra, totalizando amostra final de 23 artigos.

Conclusão: A presente revisão evidenciou a necessidade de aprimorar estratégias de comunicação dos profissionais de saúde e a maneira como as informações são fornecidas aos adolescentes e adultos jovens, pois é imprescindível que seja de forma individualizada e adaptada à idade. A equipe de saúde deve se atentar aos assuntos pertinentes a cada fase de desenvolvimento dos pacientes, como sexualidade e drogas, e abordá-los sempre que possível. É preciso ouvir e respeitar as opiniões dos adolescentes e adultos jovens, considerando-as durante cada fase de seu tratamento.

Abstract

Objective: To describe the scientific evidence regarding the demands and needs of adolescents and young adults undergoing oncological treatment.

Methods: Integrative literature review with a search strategy applied to PubMed®, *The Cochrane Library*, and the *Biblioteca Virtual em Saúde*. Inclusion criteria were articles available online in full related to the demands and needs of adolescents and/or young adults during oncological treatment in English, Portuguese, and Spanish, published between January 1, 2010, and August 31, 2020.

Results: A total of 1,397 articles were obtained. After reviewing titles and abstracts, 1,332 were excluded. Of the remaining, 2 were not found in full, and 40 were excluded after full-text reading, resulting in a final sample of 23 articles.

Conclusion: This review highlighted the need to improve communication strategies of healthcare professionals and the way information is provided to adolescents and young adults. It is essential that communication is individualized and adapted to their age. The healthcare team should address relevant issues at each stage of patients' development, such as sexuality and drugs, whenever possible. Listening to and respecting the opinions of adolescents and young adults is crucial, considering them during each phase of their treatment.

Resumen

Objetivo: Describir las evidencias científicas en relación con las demandas y necesidades de adolescentes y adultos jóvenes en tratamiento oncológico.

Métodos: Revisión integrativa de la literatura cuya estrategia de búsqueda se aplicó en las bases de datos PubMed®, *The Cochrane Library* y la *Biblioteca Virtual em Saúde*. Los criterios de inclusión fueron: artículos disponibles en línea relacionados con las demandas y necesidades de adolescentes y/o adultos jóvenes durante el tratamiento oncológico en inglés, portugués y español, publicados entre el 1 de enero de 2010 y el 31 de agosto de 2020.

Resultados: Se obtuvieron 1,397 artículos. Tras la lectura de títulos y resúmenes, se excluyeron 1,332. De los restantes, 2 no se encontraron en su totalidad y 40 se excluyeron después de la lectura completa, resultando en una muestra final de 23 artículos.

Conclusión: Esta revisión destacó la necesidad de mejorar las estrategias de comunicación de los profesionales de la salud y la forma en que se proporciona información a adolescentes y adultos jóvenes. Es imprescindible que

Keywords

Adolescent; Young adult; Medical oncology; Therapeutics; Review

Descritores

Adolescente; Adulto jovem; Oncologia; Terapêutica; Revisão

Descriptores

Adolescente; Adulto joven; Oncología médica; Terapéutica; Revisión

How to cite:

Souza MC, Campos DR, Boldrin E. Demands and needs of adolescents and young adults under oncological treatment. *Rev Soc Bras Enferm Ped.* 2023;23:eSOBEP20230008.

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Conflict of interest: nothing to declare.

Submitted: May 29, 2023 | Accepted: Dec 20, 2023

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DOI: 10.31508/1676-379320230008

la comunicación sea individualizada y adaptada a su edad. El equipo de salud debe prestar atención a temas relevantes en cada etapa del desarrollo de los pacientes, como sexualidad y drogas, abordándolos siempre que sea posible. Escuchar y respetar las opiniones de los adolescentes y adultos jóvenes es crucial, considerándolas durante cada fase de su tratamiento.

Introduction

The Child and Adolescent Statute defines adolescents as those between 12 and 18 years old. However, the World Health Organization (WHO) defines adolescence as the period between 10 and 19 years old. From 20 to 24 years old, they are called young adults. According to the Progress Review Group, carried out by the National Cancer Institute of the United States and the Livestrong Foundation, adolescents and young adults (AYA) were defined as those aged between 15 and 39 years.^(1,2)

This phase focuses on building skills that will support AYA as they advance into adulthood. It is during this period that they learn to adapt to new intellectual abilities, balance the influence of peers and family, adjust to society's behavioral expectations, internalize a system of personal values, investigate their sexuality and prepare for the job market and other roles.⁽³⁾

Cancer diagnosis and treatment can affect AYA development. Newly acquired intellectual skills can regress under the pressure and trauma of experience. Relationships can fall apart from lack of interaction, and relationships can become complicated by increased dependence. Newly developed sexual relationships may be suspended. Furthermore, body image can be compromised. Lastly, future plans can be impacted due to the suspension of studies and work and the development of a sense of self that can be severely impacted by the inability to behave like a normal young person.⁽³⁾

In Brazil, AYA represent an underestimated group of patients, which results in a lower probability of receiving diagnosis and treatment within the appropriate time frame. Survival rates for young people living with cancer are lower than those seen for individuals under the age of 15 or adults over the age of 29.⁽⁴⁾

AYA are in a time of transition and are known to inhabit a "no man's land" as they are not under the focus of either pediatric oncology or clinical oncology. Thus, health services still face challenges in managing AYA cancer.⁽⁵⁻⁸⁾

It is not yet evident in the literature whether AYA's vision is taken into account during care plan.

Therefore, this integrative review aimed to describe scientific evidence regarding the demands and needs of AYA under oncological treatment.

Methods

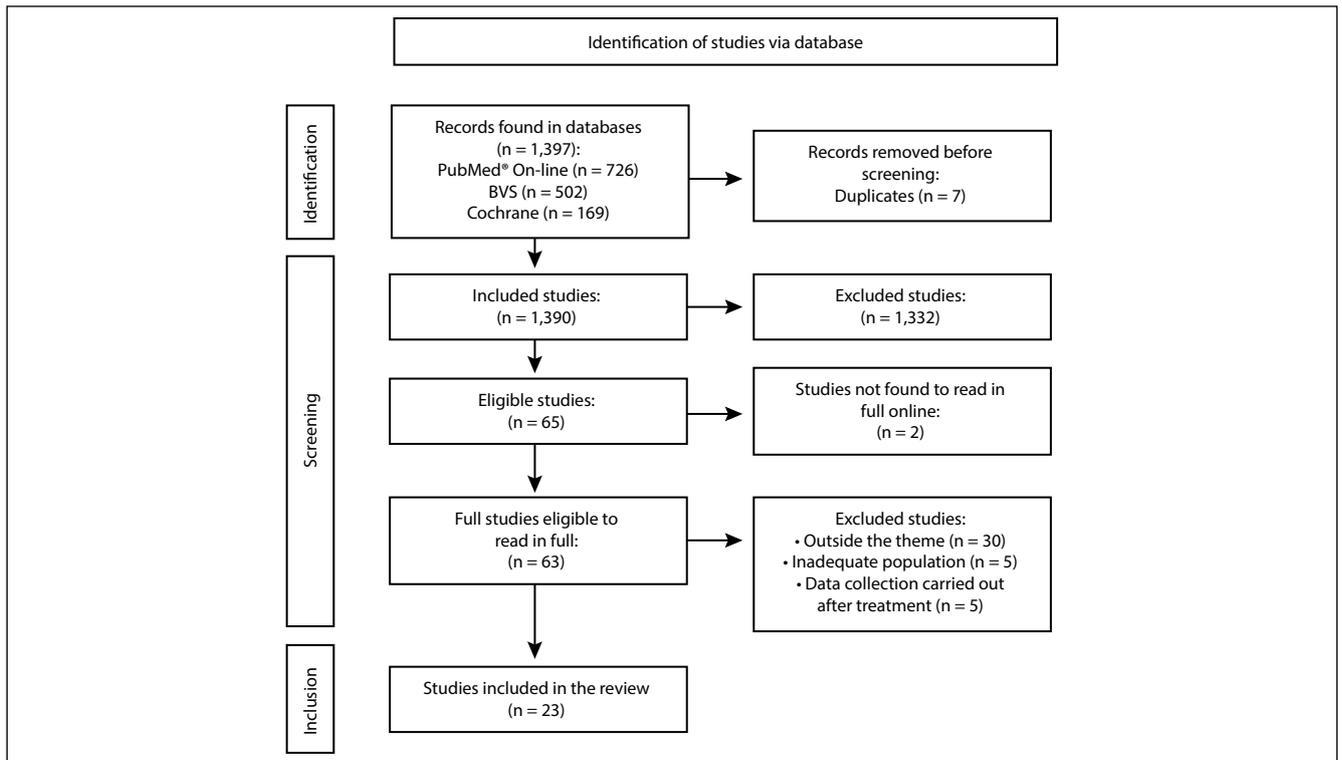
This is an integrative literature review, a method that is part of Evidence-Based Practice (EBP).⁽⁹⁾ The study was conducted using the following guiding question: What are AYA's demands and needs during cancer treatment? The search strategy was established according to the PICO strategy, and the descriptors were defined according to the Medical Subject Headings (MeSH). Three databases were used to select the articles, such as PubMed®, The Cochrane Library and the Virtual Health Library (VHL). Articles published and available in full online, in English, Portuguese and Spanish published between January 1, 2021 and August 31, 2020, which addressed the demands and needs for the care of adolescents and/or young adults (10 to 39 years old) during cancer treatment, were included.

Results

Through a search in the databases, 1,397 articles were obtained. After reading their titles and abstracts, 1,332 (95%) were excluded. Of the remaining 65 articles (5%), 2 were not found online, totaling a sample of 63 articles, which were read in full by peers. Afterwards, 40 were excluded, as 30 did not address the desired topic, five focused on healthcare professionals and/or parents, not taking patients' opinions into account and five analyzed AYA after treatment. Finally, 23 articles (1.61%) were included in the final sample.

From the analysis of the 23 articles, the relevant information presented in Chart 1 was extracted.

The word cloud (Figure 2) was created based on the terms that were most repeated in all articles and expressed the main demands and needs of AYA under oncological treatment. Medical information refers to treatment, procedures, protocols and prognosis,



VHL - Virtual Health Library.

Figure 1. Article selection flowchart

and the best means of circulating this information were websites. The deficiency in this information occurs mainly in the context of fertility and late effects. Communication, trust and honesty were said to be necessary in the AYA's relationship with healthcare professionals, in addition to empowerment for decision-making, independence, autonomy and being heard. Follow-up care was cited as necessary to deal with the changes brought about by cancer and treatment. Ambience concerns being treated in a dedicated unit for AYA, with psychological support, privacy and specialists in oncology and AYA.

Regarding the indexing of research, it is clear that most studies were indexed in VHL (65.2%), seven (30.4%) were in PubMed® and only one was in Cochrane. The age of AYA ranged from 12 to 39 years. Three studies had a sample with participants aged 10 to 20 years; 12 studies had participants aged 14 to 29 years; and five studies had participants aged 14 to 39 years. Even with the wide age range, most of the demands and needs found were common among AAY, except issues about financial support, labor rights, child care and fertility, which were more related to young adults.

Discussion

AYA have many expectations regarding information about their pathology and treatment. Obtaining information is closely linked to knowledge production and active participation of AYA in their treatment.⁽³⁴⁾

Being informed about late effects can generate stress and anxiety, however it is understood that these negative consequences outweigh the benefits of understanding what could happen. A study carried out with cancer survivors showed that adolescents may not be prepared to talk about possible health risks, and guidance must be individualized and adapted to each stage of treatment.⁽³⁵⁾

AYA want to be informed about all the details of their treatment. When it comes to fertility, organizations such as the American Society of Clinical Oncology have created guidelines to facilitate the reproduction of information about cancer-related infertility. Two strengths stand out: AYA need to know the potential gonadotoxic effects of their cancer and/or treatment as soon as possible and, if they want to understand the options for preserving their fertility, they should be referred to reproductive experts.⁽³⁶⁾

Chart 1. Synthesized information from the articles included in the study

Authorship	Place of publication and level of evidence ⁽¹⁰⁾	Main results
Stinson et al. ⁽¹¹⁾	Toronto, 6	All groups highlighted the importance of knowledge about cancer, transition, appropriate healthcare for adolescents and support to help self-manage the disease.
Zebrack et al. ⁽¹²⁾	Oregon, Texas and California, 5	Many AYA do not have their psychosocial needs met. Time pressure, excessive caseload, and limited access to this service, particularly in adult care settings, may prevent trained psychosocial healthcare professionals from assessing and providing appropriate services.
Palmer et al. ⁽¹³⁾	Australia, 6	The measures developed represent the best available in Australia. They highlight a clinically recognized minimum standard of care that all young cancer patients, regardless of treatment site, are entitled to receive.
Keegan et al. ⁽¹⁴⁾	Washington, 7	The workshop provided an important synthesis of research and clinical practice-based perspectives on the needs of AAY with cancer. The need to leverage data sources to better understand and improve care was emphasized, with an emphasis on late and long-term effects, fertility preservation, psychosocial issues and improved quality of life.
Olsson et al. ⁽¹⁵⁾	Sweden, 6	These AYA have unmet special needs, whether in pediatric or adult units. Professionals need greater knowledge to assist them, including age-appropriate information (sexuality and fertility).
Cheung et al. ⁽¹⁶⁾	Ann Arbor and Los Angeles, 7	From the perspective of AAY with cancer, optimal cancer treatment and utilization of supportive information and resources require that cancer support programs foster meaningful connections between patients. Findings suggest that resources should provide AYA with practical knowledge and skills needed to navigate the healthcare system and advocate for themselves. Given patient interest in social media, future research should further investigate the optimization of online resources.
Barakat et al. ⁽¹⁷⁾	Philadelphia, 6	The most common themes for challenges were treatment and associated physical changes, barriers to pursuing academic/vocational goals, and social isolation. Preferred modalities for dissemination are in person and message boards/Facebook. Lack of awareness was identified as an impediment to accessing available services.
Bibby et al. ⁽¹⁸⁾	Australia, 5	The findings highlight the need for age-appropriate information and treatment facilities, access to emotional support services and contact with peers. Fertility information and services are a priority issue for this group.
Essig et al. ⁽¹⁹⁾	Switzerland, 6	Professionals have a different perspective from AAY cancer survivors and parents about the factors that hinder communication between them. Although there is agreement on what constitutes good communication by doctors and nurses, they have different goals when communicating with parents and patients.
Fardell et al. ⁽²⁰⁾	Australia, 7	An AYA care model requires consideration of all associated factors (patient, service and system). Success includes healthcare professionals with expertise in AYA cancer, a multidisciplinary approach, coordinated care, integrated psychosocial support, and age-appropriate information.
LaRosa et al. ⁽²¹⁾	Florida, 6	Perceived barriers were management of physical and psychological symptoms, lack of communication about transition after treatment, and lack of information about financial and insurance issues. A website or patient portal was cited as an important resource, as was a support system made up of family members, doctors and nurses.
Kaal et al. ⁽²²⁾	Netherlands, 6	Low levels of empowerment were associated with low levels of autonomy and social support, female sex and coping difficulties.
White et al. ⁽²³⁾	Australia, 6	Although caregiving experiences were generally positive for most AAY, assisting youth cancer services was associated with better communication and supportive care experiences.
Georgievski et al. ⁽²⁴⁾	Canada, 6	Photovoice is an important tool for working with adolescents with cancer. It provides connections with colleagues who socialize, develop friendships and support networks within the hospital, providing an environment where adolescents support each other by sharing difficult experiences, helping to foster resilience in the process. The stories shared provide therapeutic knowledge and important insights into how professionals can work to meet the evolving psychosocial needs of adolescents with cancer.
Mack et al. ⁽²⁵⁾	Massachusetts, 6	Most AYA value receiving prognostic information that is positively related to aspects of well-being. However, the majority overestimates the chances of a cure, highlighting the importance of improving communication with this population.
Marshall et al. ⁽²⁶⁾	United Kingdom, 6	The adult environment was classified as lonely, exposing them to distressing issues and without support from the team. It was reported that there were few facilities for participants to engage in "normal" AAY activities, and their access to the outside world was restricted. If they could choose, everyone would prefer a specialized environment.
Siembida et al. ⁽²⁷⁾	Connecticut, 6	Need to consider adolescents with cancer separately from older and younger patients. The perception of service was driven more by the relationship with professionals than by their own involvement.
Christen et al. ⁽²⁸⁾	Switzerland, 4	Survivors reported that they needed more information, especially about late effects, and that they preferred it to be given orally or in writing.
Smith et al. ⁽²⁹⁾	United States, 7	The study provided evidence to the oncology and AAY research community that population-based work on this topic is feasible and sets the stage for additional research to understand and meet the needs of this population.
Bergeron et al. ⁽³⁰⁾	California, 7	Through education, peer outreach and AYA-specific events, the program supports patients and families through the challenges of cancer, empowering them to take ownership of their treatment and invest in their survival.
Kohi et al. ⁽³¹⁾	Tanzania, 6	Participants expressed emotional, physical and financial concerns about care and early cancer treatment. The need for improved cancer care and treatment in the hospital and greater education about cancer was identified.
Mack et al. ⁽³²⁾	Massachusetts, 6	Nearly a quarter of patients expressed regret about initial treatment decisions. Although some AYA were not engaged in the decision, the patient/oncologist relationship, with trust and understanding, can be protective for regret.
Friebert et al. ⁽³³⁾	United States, 2	Families had a poor understanding of adolescents' values regarding their own end-of-life care, such as when to initiate conversations about it, and their preferences. Planning ahead for pediatric care can minimize these misunderstandings.

AYA - adolescents and young adults.

Conclusion

Analysis of the review articles highlighted the need to improve the communication strategy adopted by healthcare professionals as well as the way in which information is conveyed to AYA. This involves exploring their preferred communication channels, making information more accessible, personalized and dynamic. It is essential that they are also age-appropriate and aligned with each stage of treatment, taking into account the individual opinions of each patient and enabling them to be leading actors of their therapeutic plan. As this is a period marked by changes and transitions, the healthcare team must remain attentive to issues relevant to each phase of AYA development, addressing them whenever possible. It is concluded that it is essential to listen to and respect the needs and demands of each person, empowering them as protagonists of their own journeys. It is evident that this builds a bond of trust between professionals and patients, resulting in greater patient adherence to their treatment.

Acknowledgements

To patients and families, to our friends, to the NAP of Hospital de Amor infantil-juvenil, to the IEP library, especially Martins Fideles and the coordination of to the Multidisciplinary Residency Program in Pediatric Oncology at Hospital de Amor de Barretos.

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