Perspectives on Organizing Long-Term Monitoring Care for Survivors of Childhood Cancer

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Perspectivas da Organização dos Cuidados de Monitoramento de Longo Prazo para os Sobreviventes de Câncer Infantojuvenil

Perspectivas de la Organización de los Cuidados de Monitoreo a Largo Plazo para Sobrevivientes de Cáncer Infantil

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ABSTRACT

Introduction: Individuals with a history of childhood cancer have 10- to 20-fold higher risk of developing a second cancer during their lifetime. The late effects of cancer treatment may appear in the short or long term and can cause significant consequences for patients who undergo it. **Objective:** To identify the needs and perspectives of professionals about the organization of follow-up care for long-term survivors of childhood and adolescent cancer at a high-complexity oncology center in Rio de Janeiro. **Method:** Situational analysis through a qualitative approach based on Denzin's theoretical framework of interpretive interactionism. Data were collected through a structured interview guide and later discussed across three categories: elements of survivor care, intersectoral collaboration and comprehensiveness of care, and the need for psychosocial support. **Results:** The follow-up of survivors is challenging due to disagreements among professionals on selection criteria. The need for personalized care plans, effective communication, and the promotion of self-management stands out as essential to ensure continuous and comprehensive care. **Conclusion:** The study's findings identified as main challenges the lack of consensus among professionals about the care that should be offered to survivors, as well as limited knowledge on the concepts of survivorship, long-term follow-up, and selection criteria. Professionals pointed out as perspectives the improvement of communication between different levels of healthcare and the need for an integrated structure capable of effectively addressing the specific survivors' demands.

Key words: Health Personnel; Transitional Care; Cancer Survivors; Minors; Young Adult.

RESUMO

Introdução: Indivíduos com história de câncer na infância apresentam 10 a 20 vezes maior risco de desenvolver um segundo câncer durante a vida. Os efeitos tardios do tratamento do câncer podem surgir em curto ou longo prazo e causar consequências significativas para os pacientes que se submetem a ele. **Objetivo:** Identificar as necessidades e perspectivas dos profissionais para organização dos cuidados de monitoramento para os sobreviventes de câncer infantojuvenil de longo prazo de um centro de alta complexidade em oncologia do Rio de Janeiro. **Método:** Análise situacional, envolvendo abordagem qualitativa segundo o referencial teórico do interacionismo interpretativo de Denzin. Os dados foram coletados por meio de um roteiro de entrevista estruturado e discutidos posteriormente em três categorias: elementos do cuidado aos sobreviventes; intersetorialidade e integralidade do cuidado; necessidade de apoio psicossocial. **Resultados:** O acompanhamento de sobreviventes enfrenta desafios em razão de divergências entre profissionais sobre critérios de seleção. Destaca-se a necessidade de planos de cuidado personalizados, comunicação eficaz e promoção da autogestão para garantir um atendimento contínuo e abrangente. **Conclusão:** Os achados do estudo permitiram identificar, como desafios, o dissenso dos profissionais sobre os cuidados que deveriam ser ofertados aos sobreviventes, o desconhecimento sobre os conceitos de sobrevivência, o monitoramento em longo prazo e os critérios de seleção. Os profissionais apontaram como perspectivas a melhora da comunicação entre os diferentes níveis de atenção à saúde e a necessidade de uma estrutura articulada que possa lidar eficazmente com as demandas específicas dos sobreviventes.

Palavras-chave: Pessoal de Saúde; Cuidado Transicional; Sobreviventes de Câncer; Menores de Idade; Adulto Jovem.

RESUMEN

Introducción: Las personas con antecedentes de cáncer infantil presentan un riesgo de 10 a 20 veces mayor de desarrollar un segundo cáncer a lo largo de su vida. Los efectos tardíos del tratamiento oncológico pueden aparecer a corto o largo plazo y generar importantes consecuencias en los pacientes. **Objetivo:** Identificar las necesidades y perspectivas de los profesionales respecto a la organización de los cuidados de monitoreo a largo plazo para los sobrevivientes del cáncer infantil y juvenil en un centro oncológico de alta complejidad en Río de Janeiro. **Método:** Análisis situacional con enfoque cualitativo basado en el marco teórico del interaccionismo interpretativo de Denzin. Los datos se obtuvieron mediante entrevistas estructuradas y fueron discutidos en tres categorías: elementos del cuidado a los sobrevivientes, intersectorialidad e integralidad del cuidado, y necesidad de apoyo psicosocial. **Resultados:** El seguimiento de los sobrevivientes enfrenta desafíos derivados de la falta de consenso entre los profesionales sobre los criterios de selección. Se evidenció la necesidad de planes personalizados, una comunicación más efectiva y la promoción de la autogestión para garantizar una atención continua e integral. **Conclusión:** Los hallazgos del estudio permitieron identificar desafíos como la divergencia de los profesionales acerca de los cuidados que deberían ofrecerse a los sobrevivientes, la carencia de conocimiento sobre los conceptos de supervivencia, el monitoreo a largo plazo y los criterios de selección. Los profesionales destacan como perspectivas la mejora de la comunicación entre los diferentes niveles de atención a la salud y la necesidad de una estructura articulada capaz de responder adecuadamente a las demandas de los sobrevivientes.

Palabras clave: Personal de Salud; Cuidado de Transición; Supervivientes de Cáncer; Menores; Adulto Joven.

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INTRODUCTION

Child and adolescent cancer (0-19 years) or childhood cancer is a group of several diseases having in common the uncontrolled growth of abnormal cells in any part in the organism. Unlike adult cancer, it is predominantly embryonic, usually affecting blood cells and conjunctive, epithelial, muscle and nervous tissues[1].

The main types of childhood cancer are leukemias, tumors of the central nervous system and lymphomas. Embryonic tumors (neuroblastoma, renal tumors and retinoblastoma) affect children and adolescents aged 15-19 years, being epithelial tumors – thyroid, carcinoma and melanomas – the most frequent. Statistically, cancer is the primary cause of death by disease among 0-19 years children and adolescents in Brazil. Whether earlier detected, up to 80% of the cases are curable[1,2].

It is estimated that 7,560 new cases of childhood cancer will occur in Brazil in the triennium 2026-2028, 3,960 in boys and 3,600 in girls. This difference reveals the incidence and mortality pattern higher in boys as well as deaths (1,311 against 995 in girls) registered in 2023[1].

Social disparities significantly influence the outcomes of childhood cancer in Brazil, says the literature. Race, socioeconomic conditions and poor health infrastructure contribute to late diagnosis and worst clinical results, especially in Black, Indigenous children living in underserved regions[1,2].

Globally, according to the Global Cancer Observatory of the International Agency for Research on Cancer (Iarc) it is estimated that 280 thousand children and adolescents have been diagnosed with cancer, nearly 110 deaths, although these figures could be even higher due to underreporting mostly in low and middle-income countries[3].

Individuals with a history of childhood cancer have 10- to 20-fold higher risk of developing a second cancer during their lifetime. The time the second cancer appears is not well defined but 3% to 12% of the children develop in the first 20 years[4]. The ongoing improved survival over the past 40 years for pediatric and adult cancers has resulted in populations of cancer survivors with unique needs[4,5].

The literature described the concept of "seasons of survivorship" which included acute survival or the period after diagnosis; extended survival, a time after completion of treatment and permanent survival when recurrence seems highly unlikely yet long-term effects of treatment continue[4].

For example, radiotherapy can reduce child development and provoke scoliosis, fibrosis, xerostomia, retinopathy, early coronary disease and risk of sterility[5]. Chemotherapy can cause cardiomyopathy, cardiac arrest, hemiplegia, seizures, peripheral neuropathy[5]. Surgery can compromise the immune function, functional problems, deformity and psychological effects related to amputation, impotence and incontinence[5,6].

Adolescents and young adults diagnosed with cancer between 15 and 19 years are collectively a distinct subgroup with high risk of morbidity and mortality after 40 years of age[7]. Control begins at the end of the oncologic disease when remission starts. Although no consensus exist, patients are considered cured after five years of control to mitigate the treatment late effects.

The objective of this study is to identify the needs and perspectives of health professionals to organize monitoring care for long-term childhood cancer survivors at a high complexity center in Rio de Janeiro.

METHOD

The present study followed the Consolidated Criteria for Reporting Qualitative Research (COREQ)[10]. It is a situational analysis involving qualitative approach conducted at a reference institution to diagnose and treat childhood cancer in Rio de Janeiro.

The study adopted the theoretical referential of Denzin interpretive interactionism that utilizes the understanding individuals have about their lives[11]. The meanings individuals access for their domains are based on their interpretation, social interactions and how they construct a social order negotiated and agreed upon[11].

For Denzin, individuals not only respond or adjust to the social world but can contribute for its construction. Their development is based on the assumption that human actions occur towards the other, with the other and from the other within mutual processes that result in interactional experiences mediated by symbols and language[11].

Therefore, the study included health professionals involved in caring for onco-pediatric patients as physicians, nurses, social workers and psychologists. Only those directly involved in the transition of care have been enrolled, regardless of other professional categories. Exclusion criteria were professionals with less than five years of experience and non-oncology experts. Eventually, 15 professionals have been enrolled, being five nurses, five female doctors, three social workers and two female psychologists.

The narratives of the participants were identified by codes indicating professional category and sequential number (ENF1, MED2, SS1, PSI1) to preserve anonymity and allow interpretive reading across different professional formations.

Prior to the interviews, the professionals were briefed on the study's objectives, procedures involved and their rights described in the informed consent form (ICF) and to clarify potential doubts.

Data were collected from July to December 2023 through a 10-question structured interview portrayed in Chart 1. The interview was conducted in-person at the institution's premises, in a secluded room to ensure privacy and confidentiality. The interview was recorded and later transcribed in Microsoft Word to preserve the participants' narrative. The interview lasted from 7 to 20 minutes.

The data collected were coded by content analysis with themes earlier defined based on the existing literature and the interview questionnaire[12]. Initially, eight codes have been identified: knowledge health professionals had about the organization of the care to the survivors, questions related to the absorption by the network, resources to structure a plan and crucial information, emphasis to the organization of the care, involvement of non-expert professionals, specific action of the multidisciplinary team, challenges of the institution, impacts on the mental health of survivors and families. Later, these codes were aggregated in three categories of analysis: elements of care to the survivors, intersectoriality and integrality of the care, and need of psychosocial support

The Ethics Committee approved the study, report number 6,128,698 (CAAE (submission for ethical review: 69996123.9.0000.5274) in compliance with Directives 466/2012[13] and 510/2016[14] of the National Health Council (CNS).

RESULTS AND DISCUSSION

The age range of the participants varied between 24 and 51 years old, predominantly 37-51 years. Time of professional formation was from 10 to 27 years while oncologic professional practice varied from 5 to 21 years. Nurses (n = 5) had between 11 and 27 years of formation and from 20 to 21 years of oncologic experience. Physicians (n = 5) had between 15 and 25 years of formation and oncological practice between 10 and 20 years. Social workers (n = 3) had between 10 and 23 years of formation and oncological experience from 5 to 15 years. Psychologists (n = 2) had between 13 and 25 years of formation and from 13 to 15 years of oncological practice.

ELEMENTS OF CARE TO SURVIVORS

Findings related to the convictions health professionals had on selection criteria of survivors and organization of long-term care have emerged in this category. The participants diverged about who should be followed up at health primary attention (HPA), some advocated that all survivors should be followed up and others preferred the selection based on specific clinical criteria. Criteria of risk stratification were detected, similar to the literature, in addition to consensus about the importance of individualized care plans and communication with survivors and families.

There are survivorship care models that can be utilized to structure the care to individuals with childhood cancer

Chart 1. Questions for professionals

Number	Questions
1	Age
2	Professional category
3	Time since graduation
4	Time of work with childhood cancer patients
5	In your opinion, how patients treated for childhood cancer should be selected for long-term follow-up? Which risk factors or specific characteristics must be applied?
6	How childhood cancer can affect the mental health of survivors and their families in your perspective? How would you address these question in your clinical practice?
7	How non-experts health professionals should be involved in the follow-up of childhood cancer in your opinion? You believe these professionals are skilled and have the required knowledge to care for these patients?
8	Which resources or support you deem essential to facilitate the organization of long-term monitoring care for childhood cancer survivors in your professional practice?
9	What type of information childhood cancer survivors and their families need to know about long-term monitoring care?
10	In your perception, what are the main barriers childhood cancer survivors have to face while accessing the Institute's monitoring care?

as the model of stratification by risk of the oncologic patient in low, moderate or high[4,7].

Patients with low-risk of developing late and long-term treatment effects as those who submitted to surgery alone, to non-alkylating chemotherapy, who did not receive radiotherapy, those with low risk of recurrence and with mild or no persistent toxicity from the therapy can be followed up by non-expert oncologic professionals[4,7].

Non-expert oncology professionals may be experienced in other areas that are relevant for long-term follow-up. Therefore, there is no hierarchy of expert knowledge as each one of them is focused to specific areas that are adjusted to the user's demands[4,15].

> Patients who were exposed to least aggressive treatments and more curable diseases with low intensive care [...] These patients, overall, need to be accepted but they can be cared and involved in the network for continuous treatment later … (MED3).

> All the patients should be followed up, this is the right thing to do but resources are limited … (MED4).

A group of the professionals investigated believes all the patients need to receive long-term treatment at HPA. However, they understand that this monitoring may not be possible due to limited human and financial resources. They still comprehend that the monitoring can be hindered by the experiences the survivors had while they were being treated, with social and emotional traumas and mainly in face of a potential relapse. These aspects can make the patient insecure, compromising the referral to continuous HPA care.

This line of thinking reveals poor knowledge part of the professionals have on the selection criteria indicated in the literature, the inaccuracy of the concepts of long-term control and monitoring and the actual necessity of mental and social follow up perceived by the psychologists and social workers interviewed[4]. Different from other categories, according to Denzin, because of their knowledge and how they see the world, these professionals go beyond the clinical criteria emphasized by the literature[11].

> ... Somehow, everyone should be followed up. [...] I believe that the tumors that produce any facial or body image change are very important … (PSI1).

> … Mainly for those patients with sequelae or any disability, compromising their lives, the course of life [...] social work focuses on the rights of individuals with disability, insertion of young individuals in continuous follow-up in the job market … (SS3).

On the other hand, other professionals believe that not all childhood cancer survivors should be selected, advocating the application of clinical criteria involving the type of cancer, late effects and treatment and/or disease related sequelae.

> They should be selected after the treatment applied, for instance, there are some tumors that are only surgical. Therefore, the surgical patient that manages to be disease-free does not face this reality … (ENF5).

> Patients who receive radiotherapy, with cancer predisposition syndromes, in intense chemotherapy, those with recognized sequelae of the disease and treatment… (MED3).

The literature presents the criteria of moderate and high risk for the development of late effects, consistent with those presented by part of the professionals. For moderate risk: low or moderate dose of alkylating agent, low or moderate dose of radiotherapy, autologous stem-cell transplantation, moderate risk of recurrence, moderate toxicity or no persistent therapy toxicity[4].

For high risk, the criteria are: high dose of alkylating agent, high dose of radiotherapy, allogeneic stem-cell transplantation, high risk of recurrence, persistent therapy toxicity in multiple organs[4].

After the stratification of risks and selection of survivors, it is crucial to implement an individualized care plan for everyone to promote quality of life to these individuals. Each cancer survivor should have a plan initiated by an oncologist after the end of the treatment[7]. The plan should include a summary of the treatment, expected late effects, type of monitoring and surveillance parameters, relevant contact information and pending necessities identified by the survivor[7].

> ...they must understand that in the future, depending on the treatment, some kind of neoplastic alteration related to the treatment may occur, this can't be forgotten or a second disease … (ENF5).

> ... first, understand what was the name of the disease, the treatment applied and the consequences this treatment can cause, talk about late toxicities... (MED3).

Unanimously, all of them agreed that communication with the survivors and their families is crucial and the construction of a material that consolidates pertinent information is a strong ally for health promotion. Despite being briefed about these aspects when the treatment is being applied, they go unnoticed because of factors associated with emotional and social fragility, level of understanding of the families and excess of information[16].

> … They need to be well guided because sometimes abandonment occurs, the child receives a prognosis of cure, disease-free and the family abandons the follow up … (ENF2).

The implementation of long term follow up care plan promotes interactions among patients and professionals, encouraging the active participation of the patients in self-care[4]. This results in a continuous, ample assistance, of better quality and possibly more cost-effective than traditional models where health professionals manage all the aspects of the patient care[7]. Therefore, a self-management-based care model can be useful and applied in the course of cancer treatment.

Regardless of the strategy adopted, the Institute of Medicine (IOM) designed the essential components of an ideal model of shared care: preventive measures and surveillance methods to detect new or recurring cancers, proper interventions to control side effects, defined pathways that specify the coordination or distribution of care among experts and professionals of HPA[17].

INTERSECTORIALITY AND INTEGRALITY OF CARE

The interviewees revealed that cancer survivorship care is marked by structural limitations, social disparities and challenges to articulate different levels and sectors of the attention network. The lack of specific public policies focused to survivors, overload of specialized services, fragilities of care sharing with HPA in addition to barriers related to the knowledge that oncology and non-experts professionals have. In addition, suggestions to improve the care network have emerged, including the strengthening of intersectoral communication, creation of reports, standardization of care plans, improvement of the transition to clinics for adults and, in some cases, the proposal to create a unit focused exclusively to survivors.

Care to cancer survivors faces lack of time and resources in oncology and primary care environment, patients' preferences, financial concerns and reimbursement issues[4]. In Brazil, social disparities are an additional problem that impact the process health-disease, morbidity, mortality, quality and extension of life. Regional disparities become evident, since the North and Northeast regions are listed in practically every indicator as the most underserved regions of the country[18].

In March 2022, the national policy of pediatric oncology was created to strengthen the regulation processes to ensure access to early diagnosis, full treatment, rehabilitation and family-centered care, promotion of scientific researches and use of therapeutic protocols identifying late effects of survivors[19].

> ... you may potentially reinsert yourself socially and live your life regularly, it is essential that they are aware that oncologic treatment is a period, a phase, you must be connected to the network, basic attention, to care for your health in general… (SS2).

> … the disease has also consequences on the life of the individual and we need to pay attention to these implications, focus on this issue too [...] We try to organize to meet these demands, but I think it has to be formalized as a policy … (SS3).

The literature indicates that the model exclusively focused on the oncologist concentrates care in specialized environments. The extensive utilization of oncologic services during the post-treatment survival phase significantly overburdens the current capacity of cancer centers, making unsustainable to meet the unmet survivors demands. The rising incidence of new cases of cancer and limited specialized human resources to meet this demand are additional problems[20].

> ... There is an expertise associated with oncology and not necessarily the network is able to meet these situations without creating further delays and harms to the follow-up of these patients … (SS2).

> ... I'm used to see a patient at the emergency who is cancer-free and asks for medical attention because of a sore throat, fever, the Institute eventually absorbs this patient but fails to absorb another patient (ENF4).

> ... it is the assignment of limited public resource, it's the bioethical criteria of justice and the direction does this quite well but we know it is a burden for the survivor … (MED1).

A strategy to reduce the overburden of specialized attention is sharing care with HPA. The counter-reference of the oncologist to the primary attention team should be smooth to avoid the survivor to feel abandoned in addition to reducing a potential perception that they are being assisted by a lesser instance[7,20,21].

Low confidence on HPA health professionals is a recurring challenge for the implementation of alternative care models[20,21]. Care sharing was pointed out by the interviewees as a fragility phase for long-term monitoring care.

> … Patients who ended the treatment are kind of lost amidst basic health [...] she can't be abandoned by the public network … (ENF4).

> I think this is not necessarily associated with knowledge, knowledge is something you go to basic attention to exchange [...] the patient is not going to be ours, this institution is quite centralizing … (PSI1).

> ... I think if basic attention professionals are guided and treatments correctly clarified, it is possible to follow up, and to avoid overloading tertiary service … (MED2).

On the other hand, inappropriate knowledge oncologists have is a significant barrier to provide high quality services. The literature indicates that both oncology providers offer non-oncological care below the ideal, and non-skilled professionals provide oncologic follow up care below the ideal[4]. All of them need to be skilled and chosen to provide high level shared care.

> Not all oncology professionals are able, in the sense of attentive, to try to understand what survival means, just like the non-experts … (MED3).

The professionals suggested strategies to improve the care network, including the transition to clinics for adults, adequacy of human resources, creation of detailed reports for HPA, strengthening the communication among levels of attention, standardization of care plans, expansion of the long-term outpatient and implementation of a survivor-targeted unit.

Broad strategies as the creation of a specialized unit require high investment and are difficult to implement. Actions to organize the transition of pediatric survivors to clinics for adults and standardize an institutional care plan depend more of an organizational and human resources culture, being more viable in the short and medium terms. These can evolve with working groups and well-defined goals.

Some strategies suggested require reflection specially about transition of care. Inadvertent referral of pediatric survivors patients to clinics for adults may overlook children and adolescents specificities. It is essential to know the particularities of these phases, most of all the unique demands of the adolescents that do not fully fit the pediatric or adult models[22,23].

Likewise, the idea of an exclusive unit for survivors, although being a progress in the continuum of care, requires attention to avoid generalizations and for the care to be actually matched to the necessities of each age range[22,23].

NECESSITY OF PSYCHOSOCIAL SUPPORT

In this segment, the professionals highlight that the necessity of psychosocial support emerges as a core element in the care of oncological pediatric patients and their families, contributing with the perception of cancer stigma still strongly associated with death, suffering and exclusion. This stigma intensifies fear and insecurity since diagnosis. Therefore, they devise mitigation strategies as empathetic listening, proper guidance and clear information. The professionals point out that fear of recurrence is the most prevalent emotion among survivors and family.

Cancer is still widely associated with death and suffering, creating stigma and emotional impact both in patients and family. This stigma reinforces fears and exclusions, being essential to deal with it since diagnosis through listening and proper guidance[24,25].

> Stigma involves the disease, it is something that increases exponentially, fear, the pain because of the disease,[...] fear of relapse must be overwhelming … (ENF2).

> ... Every time the patient has to do a blood test or any other exam [...] he is always afraid the cancer is back (ENF4).

Although the parents were not listened in the present study, the literature indicates they frequently live with feelings of guilt, many times internalizing the idea they somehow failed in some aspect that could have contributed to the appearance of the disease or a negative outcome of the treatment as death or permanent sequelae[25,26]. Guilt as a moral feeling associated with the responsibility perceived because of a damage can compromise the experience of care and coping with the sickening process[25,26].

> ... Parents who are deeply vested in their maternal or paternal functions believe it was their fault. What I failed to see, what I failed to do … (PSI1).

> … They say, how can I feel bad now that cancer has gone, how can I be emotionally distraught, I can't! It is not true, a person can cope well during treatment and feel bad later, it can happen … (PSI2).

Likewise, the survivors themselves live the paradox of survivorship: they feel a profound relief for overcoming the disease but also frustration and suffering in face of permanent functional limitations that contrast with full cure and resuming their early life[27]. The paradox of survivorship is a complex and recurring experience among persons who overcome cancer, especially for patients who had cancer as a child or as an adolescent.

Many survivors claimed that, although "cured", they feel they are not fully healthy, an experience marked by functional limitations, self-image changes and disruption of life projects[27]. This condition puts them in an ambiguous place where biomedical cure is not a synonym of well-being. Survivorship requires a novel process of subjective and social reconstruction, demanding continuous psychosocial support, listening, well-coming and institutional policies that acknowledge the specificities of this group[27].

The utilization of playful activities is essential in childhood care because it helps children who still don't fully grasp what the disease is. Playing during hospitalization reduces stress, calms, distracts and helps recovering and also is beneficial to the family. Professionals reinforce that playfulness preserves the vivacity of the child and reduces the emotional impact of the treatment[28].

> The child sees otherwise, lots of life involved there and not always they know what is going on (SS2).

On the other hand, the adolescents due to their better understanding of the disease, can live emotional suffering more intensely, which impacts the physical, psychic and social development[29]. The natural process of transition from childhood dependence into rising autonomy can be accelerated by the context health-disease, requiring early development in face of losses, decision-making and survivorship related caring[29].

> They cope with certain questions very early in their lives [...] they lose a buddy [...] sometimes they have to develop even earlier (ENF1).

> The adolescent is different, they know what is happening (SS2).

Adults who survive childhood cancer are twice more propense to report mental health adverse effects[30]. There is an increased risk of anxiety and depression among survivors and depression is more common in the first two years after diagnosis, but anxiety can be present in their lives for ten years or more[30].

Sequelae are not only physical but also appear in school performance, social bonds and family structure[30]. During treatment, the family goes through several changes and sometimes, religion and faith are present as protective factors[30]. The adversities the families live are undeniable: siblings are separated, and healthy children feel the lack of attention by their parents, parents may divorce, lose their jobs and income is reduced.

> ... Usually, the family who is close to the patient feels the impact on each and everyone. [...] Problems with the school of the siblings, care for the other brothers, parents' job and income, family income drops (SS1).

> ...There is a rupture, the rupture of the bond of the parents with their other sons. A family with father and mother, the father ends up working extra time to earn additional cash to meet the financial demand. The mother quits her job and this is a psychological burden (MED4).

According to the literature, mothers suffer more because of the disease. The emotional burden of the caring-mother is defined by the fatigue resulting from tasks involving self-care, her function with other family members, household activities and direct and indirect demands associated with her child disease[30,31]. The centrality of care, as the interviewees reported, is strongly marked by biological sex.

> ... Here in pediatrics, women are those who care more, there is a great number of mothers … (SS3).

> ... One of the mothers remained in the hospital for three months caring for her son … (ENF1).

The concentration of the care in women can't be understood as something natural or only private because it is a historically constructed phenomenon, supported by disparities that perpetuate the almost exclusive accountability of the mother[31].

This scenario, when analyzed in the context of childhood cancer and long-term monitoring, reveals the necessity of elaborating public policies that ensure continuous institutional, financial and psychosocial support to the families. Accountability of the care should not rely upon household alone. The effective participation of the State through strategies of household follow-up, socioeconomic support and intersectoral articulation is essential to ensure the sustainability of the care and quality of life of survivors and their families[18,19].

> ... The care should be multiprofessional, long-term care depends on many perspectives [...] it is an articulation of multiple knowledges … (MED3).
>
> ... Still, it is very difficult to have psychiatric support, we don't have one here … (PSI2).

Care should be inter-professional, integrating knowledges and practices and not only the single action of different professionals. The lack of psychiatrists reveals a fragility of the network but does not reduce the psychosocial attention, quite the opposite, reveals the necessity of an integrated approach of mental health involving psychology, social work, community actions and articulation with the entire psychosocial network.

CONCLUSION

The present study revealed many challenges of the daily care provided to this specific population. The needs and perspectives of the professionals about the theme are influenced by several issues. Poor knowledge of the concepts of survivorship, long term monitoring and selection criteria permeate the majority of the professionals, negatively impacting the quality of the responses.

The study limitations included the lack of other professional categories that could potentially contribute for the organization of the construction of the care to the survivors. However, it was decided to enroll health professionals directly involved in the process of transition of care.

Sometimes, the communication among different levels of health attention, according to the professionals, is insufficient, reinforcing the complexity of the scenario and the necessity of an articulated structure able to deal effectively with the specific demands of the survivors. The difficulty of integrating adequately long-term care and among different professionals suggests the importance of innovative approaches to overcome these organizational challenges.

Therefore, continued health education emerges as a core strategy to qualify the teams, promote critical reflection about the practices established and strengthen the attention network in order to ensure full care, articulated and centered in the actual needs of the survivors.

In short, this study offers a view of the perspectives of the professionals and highlights the difficulties of organizing monitoring care for long-term childhood cancer survivors. The recommendations suggested by the professionals and the literature should address specific challenges, emphasizing the urgency of innovative and collaborative strategies that overcome the barriers identified, ensuring a more effective and integral approach for this vulnerable population.

CONTRIBUTIONS

Both authors contributed substantially to the conception and design of the study, acquisition, analysis and interpretation of the data, writing and critical review. They approved the final version for publication.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

DATA AVAILABILITY STATEMENT

All content underlying the text are contained in the manuscript.

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