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The Role of Non-Governmental Organizations (NGOs) in Pediatric Cancer Care: Psychosocial, and Economic Perspectives

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Abstract

Childhood cancer represents a major global health challenge and remains one of the leading causes of death among children, particularly in low- and middle-income countries where more than 80% of cases occur. The rising incidence is attributed to factors such as population growth, aging, tobacco use, poor dietary habits, obesity, sedentary lifestyles, and exposure to infection-related carcinogens. In addition to the clinical burden, families of children with cancer face significant psychosocial and financial challenges, which can compromise both caregiver well-being and treatment outcomes. These challenges highlight the need for comprehensive strategies that go beyond medical care to include psychosocial and socioeconomic support.

Non-governmental organizations (NGOs) have emerged as important actors in addressing these gaps. Their independence, community orientation, and voluntary nature enable them to provide services that governments and healthcare systems often overlook. This review highlights the multifaceted contributions of NGOs in pediatric cancer care, including psychosocial interventions, financial assistance, advocacy, and policy engagement. Evidence shows that interventions such as cognitive behavioral therapy, problem-solving skills training, and family therapy effectively reduce caregiver stress, anxiety, and depression, while enhancing coping abilities and indirectly improving children’s treatment outcomes. At the same time, NGOs play a crucial role in reducing the economic burden of cancer care by mobilizing resources, covering out-of-pocket expenses, and facilitating access to services in resource-limited settings.

Examples from Iran, India, and global studies demonstrate that NGO-led initiatives can enhance psychosocial well-being, and increase access to healthcare. Strengthening these efforts represents a promising approach to reducing caregiver burden and improving the quality of life of children with cancer. Future research should explore sustainable models of NGO involvement, and policymakers are encouraged to integrate NGO capacities into national pediatric cancer control strategies.

Keywords: Cancer, Caregiver burden, Childhood, Non-governmental organizations

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Introduction

Childhood cancer (ChC) continues to pose a significant global health challenge, particularly in low- and middle-income nations (1-4). The anticipated increase in cancer incidence is expected to occur predominantly in developing regions, driven by factors such as population growth, aging, tobacco use, poor dietary habits, sedentary lifestyles, obesity, and infections associated with cancer (4-7). Globalization and urbanization have further intensified this trend through the aggressive promotion of tobacco—currently consumed by approximately 1.25 billion people—expanded access to high-calorie, processed foods, and reduced levels of physical activity due to shifts in workplace environments. Together, these factors have contributed to the worldwide surge in overweight and obesity. While population growth and extended life expectancy reflect major public health achievements, they also represent the primary forces behind the rising burden of cancer. Over the past five decades, advancements in living standards, nutrition, housing, food and water safety, sanitation, reproductive health, and the widespread use of vaccines and antibiotics have dramatically lowered childhood mortality and prolonged life expectancy, thereby enlarging and aging populations.

Given that most cancers develop slowly across many years, their prevalence inevitably increases with age.

Non-governmental organizations (NGOs) play a vital role in filling critical gaps that are often overlooked by governments and industry. By enhancing public awareness, advocating for policy implementation, and drawing attention to neglected health issues, NGOs provide essential support. In low- and middle-income countries, they hold considerable potential to strengthen cancer prevention and control efforts (8).

Childhood cancer, epidemiology and risk factors

Childhood cancer is an uncommon condition that develops from birth up to 14 years of age. Malignant tumors rank among the major causes of mortality in children under 14 and represent the second leading cause of death in this age group in the United States, following unintentional injuries. In developed nations, the most frequently diagnosed childhood cancers are leukemia and tumors of the central nervous system. Cancer incidence differs across populations and ethnic groups, influenced by genetic susceptibility, timing of exposure to infectious agents, and various environmental factors (9). Each year, an estimated 75 to 150 new cases of childhood cancer are reported. Globally, more than 200,000 new cases of childhood cancer are diagnosed each year, with over 80% occurring in developing countries. The World Health Organization estimates the global annual incidence at about 100 cases per million children. Overall, cancer is more prevalent in boys than in girls. Among modifiable risk factors, proper nutrition and regular physical activity play a key role in disease prevention, including cancer. Certain foods, due to their micronutrient content, contribute to cancer protection, and numerous studies have demonstrated that a healthy diet can lower cancer incidence in both adults and children. In Iran, the most frequently diagnosed childhood cancers are leukemia, brain and central nervous system tumors, as well as lymphoma, which together account for over half of new ChC cases (10). Research indicates that the incidence of childhood cancer in Iran ranges from 48 to 112 per million in girls and 51 to 144 per million in boys (11). In Tehran, the capital city, the incidence rate reached 176 per million children in 2008 (12).

Psychosocial interventions for families of children with cancer

Psychosocial interventions for families of children with cancer are recognized as an effective approach to empower family members in managing the complex challenges they encounter. The capacity of parents to adopt adaptive coping mechanisms during their child’s treatment is crucial not only for their own psychological and physical health but also for the child’s overall well-being and long-term adjustment to the illness (13). Evidence indicates that interventions such as cognitive behavioral therapy (CBT), problem-solving skills training (PSST), and family therapy can reduce parental stress and enhance coping abilities. For instance, CBT targets modification of environmental and behavioral contributors to emotional distress, while PSST equips parents with practical strategies to effectively handle challenges (13 ،14). Additionally, these interventions may indirectly improve children’s treatment outcomes by fostering a supportive family environment (15).

Early integration and continuous provision of psychosocial interventions within pediatric oncology care are vital. Various programs have been developed and assessed through meta-analytic research (13). These interventions are commonly categorized into two groups: (1) cognitive behavioral approaches, including emotion regulation, logotherapy (16), communication skills, positive thinking, brief therapy, and relaxation–resilience programs, and (2) other psychosocial approaches, such as problem-solving,

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psychosocial training, and counseling. To maximize their effectiveness, these programs must be accessible, aligned with family needs, and culturally sensitive (17). By addressing the challenges faced by parents during their child's treatment, psychosocial interventions can enhance the well-being of both parents and children (13).

CBT in pediatric oncology

All seven CBT interventions included in the studies were conducted by at least one psychologist as the lead investigator and consisted of a minimum of five 45-minute sessions. Four of the seven studies collected outcome measures at three time points: baseline, immediately post-intervention, and 2–3 months after the intervention.

Distress. Distress levels were evaluated in three studies. In two of these, mothers underwent twelve weekly individual CBT sessions, which significantly reduced distress and were associated with better adjustment outcomes (18-20). A third study targeting caregivers (93% mothers, 4.5% fathers, 2.5% grandmothers) used six individual CBT sessions, supplemented by six telephone contacts and a dedicated website, showing a reduction in psychosocial distress, especially among those with lower perceived social support at the time of the child's diagnosis (18). Depression. Three studies examined depressive symptoms. One applied ten web-guided self-help sessions (21), and another conducted eight group sessions focused on hope and depression (22). Both studies demonstrated significant reductions in depressive symptoms in the intervention groups, maintained at long-term follow-up (21, 22). The third study, which combined six individual CBT sessions, telephone follow-ups, and a dedicated website, did not produce a significant decrease in maternal depressive symptoms (18). Anxiety was assessed in three studies. A ten-week web-based guided self-help program showed sustained effects at a 12-month follow-up (21). A stress management intervention involving six individual sessions, telephone follow-ups, and website support reduced anxiety (18) However, a study employing two to three family CBT sessions found no effect on anxiety levels (23).

Post-Traumatic Stress disorder (PTSD). Four studies evaluated CBT's impact on PTSD. Two studies reported positive effects: one with ten web-based sessions and another with twelve individual sessions (20, 21). In contrast, two studies using fewer family sessions (two or three) found no improvement in PTSD among siblings or parents compared to controls (23, 24). Other outcomes. The relationship between maternal distress and children's adjustment was examined in one study using twelve weekly individual CBT sessions for mothers of children with cancer. Results indicated a significant reduction in maternal distress post-intervention, which was linked to improvements in children's internalizing symptoms (19).

Financial challenges of cancer care

Cancer care presents a profound economic burden on patients, families, and healthcare systems. The high cost of treatment, together with reliance on distress financing, creates substantial financial strain. Most cancer-related out-of-pocket expenditures (OOPE) fall directly on patients and their families, a challenge that is further intensified by inadequate health insurance coverage and limited access to publicly funded healthcare services (25).

The diagnosis, treatment, and management of cancer demand significant healthcare resources, including medications, imaging, pathology, radiology, and specialized clinical services (26-30). Beyond initial treatment, long-term follow-up for relapse surveillance, detection of secondary cancers, and psychological support impose additional pressures on healthcare systems (31). Although the financial burden of adult cancers has been extensively investigated (32-39) the economic

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implications for pediatric and adolescent/young adult (AYA) cancers remain underexplored. Evidence from adult populations consistently shows that cancer patients incur markedly higher direct medical costs than non-cancer patients, highlighting a major knowledge gap regarding financial consequences in younger age groups (26).

Importantly, willingness to pay for cancer care is strongly linked to anticipated outcomes. Recent studies (40, 41) reported that patients value improvements such as quality-adjusted life years (QALY), one-year survival, enhanced quality of life (QoL), and pain reduction. On a broader scale, indicators of economic development account for around 4% of global variation and increase disparities in breast cancer incidence and mortality by approximately 5% (42). Despite these insights, empirical studies remain scarce on how national healthcare systems prioritize cancer care within their broader economic frameworks.

Taken together, these findings underscore that financial vulnerability is a central determinant of cancer-related inequities. This burden is most pronounced in low- and middle-income countries (LMICs), where weak healthcare infrastructures and limited financial protection mechanisms amplify patient hardship, but it is also evident in higher-income settings (40).

Economic and socioeconomic burden of cancer care: Global variations and implications

Financial and socioeconomic aspects of cancer care are becoming increasingly critical, particularly for vulnerable populations and in the context of developing healthcare infrastructure (43, 44). Worldwide, the economic impact of cancer varies significantly between countries. For instance, in the European Union, the average annual per capita cost of cancer is approximately EUR 102, ranging from EUR 16 in Bulgaria to EUR 184 in Luxembourg (45). Costs also differ depending on the type of cancer, as illustrated by malignant blood disorders (46) and bladder cancer (47). Interestingly, even nations with similar GDP per capita can experience large differences in healthcare expenditures (48), reflecting not only variations in societal and individual willingness to pay but also differences in the structure and organization of healthcare systems.

Non-governmental organizations (NGOs)

NGOs are independent, non-profit entities established by groups of individuals with shared interests, and they function without direct ties to government or political parties. They act as a link between citizens and the state, giving voice to communities. NGOs are typically characterized by four main features: voluntarism, autonomy from government, non-profit orientation, and a service-based mission. These characteristics make them recognized as an “independent voice (49-53).

On the other hand, NGOs, as voluntary organizations, serve communities directly. Beyond service provision, their altruistic nature enables them to influence public policy (52) and makes them important contributors to social development (49). Their impact on civil society is multifaceted; however, systematic evaluations of their projects and programs remain limited (52). In some contexts, governments support NGO-led initiatives because these organizations possess valuable expertise in sectors such as education, rural development, community advancement, health care, and agriculture (53). Due to their smaller scale compared to governments, NGOs are often considered more flexible and efficient in both decision-making and service delivery (50).

In the field of community health, NGOs function as a complementary system to primary health care. They promote dialogue within civil society and with governmental authorities, provide relevant

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data, develop innovative approaches to demonstrate primary health care models, and strengthen communication strategies. Their contributions also include implementing programs that enhance local organizational activities and expand health services in support of human development (50). Despite these contributions, studies focusing on the role of NGOs in health remain relatively scarce worldwide. Some operate internationally and address global health issues, while others provide critical assistance during emergencies and natural disasters.

A study investigated the role of NGOs in improving treatment outcomes and life expectancy among children with cancer, where this finding (49) indicated a positive impact on survival. In India, Nimai et al. highlighted the significance of NGOs in the health sector, reporting that this was the first study to examine health expenditure in this field. Their results showed that nearly 60% of NGOs are active in health, with 31% focusing on HIV/AIDS, 29% on health system management, and 18% on reproductive, maternal, newborn, and child health (RMNCH). Additional areas of involvement included tuberculosis (6%), vector-borne diseases such as malaria and dengue (5%), tribal health programs (3%), and services for individuals with disabilities (4%) (49). Similarly, Parashar et al. emphasized the important role of NGOs in cancer control and in bridging care gaps across countries (54), while Grey et al. confirmed their contribution to cancer prevention and management efforts (55).

The role of NGOs in cancer prevention and pediatric care in Iran

Through public awareness campaigns, engagement with donors and policymakers, and fostering collaboration across institutions, NGOs contribute to healthier lifestyles, reduction of risky behaviors, and play a vital role in cancer prevention strategies. They operate financially independent of public funds while pursuing ambitious health-related goals. In Iran, NGOs such as the Mohammad Rasool Allah Charity in Yazd and the Mahak Society for Supporting Children with Cancer are key actors in advancing public health and providing care for pediatric cancer patients (49).

The effect of NGOs in in strengthening emotional resilience and promoting mental health

NGOs have become vital drivers of change in mental health advocacy, focusing not only on treatment but also on strengthening emotional resilience. Unlike purely medicalized approaches, their community-based models emphasize accessibility, cultural sensitivity, and holistic care.

In times of crisis—such as natural disasters, armed conflicts, forced displacement, and other traumatic events—NGOs provide immediate psychological first aid. Organizations like Doctors without Borders (MSF), the Red Cross, and local mental health NGOs mobilize trained professionals to deliver emergency trauma counseling, stress management support, and coping strategies, thereby helping communities maintain psychological stability.

Some NGOs extend their work to long-term rehabilitation. For instance, The Banyan in India offers mental health services for homeless individuals with severe psychiatric conditions, supporting their recovery and reintegration into society.

Research by Usha Priyanga highlights the collective contributions of 25 NGOs and numerous social workers in addressing global mental health challenges, underscoring the sector’s growing importance in bridging care gaps worldwide (56).

Ganji et al., also revealed that NGOs can enhance life expectancy of children with cancer (49).

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Discussion

Childhood cancer remains a pressing global health challenge, particularly in low- and middle-income countries, where over 80% of new cases are reported annually. The rising incidence in these regions is influenced by population growth, aging, lifestyle factors such as tobacco use, poor dietary habits, physical inactivity, obesity, and exposure to infection-related carcinogens (55, 57). While improvements in living standards and extended life expectancy reflect major public health successes, they also contribute to the increasing burden of cancer in pediatric populations. These findings highlight the need for targeted interventions that address both prevention and supportive care.

The psychosocial impact of childhood cancer on families is profound. Parents and caregivers face significant stressors, including emotional distress, anxiety, depression, and post-traumatic stress, which can adversely affect their health and the overall well-being of their children (2, 13, 19, 20). Evidence from multiple studies indicates that psychosocial interventions, including CBT, PSST, and family therapy, effectively reduce caregiver distress and improve coping strategies, thereby indirectly enhancing children’s treatment outcomes and adjustment (13-15).

Economic and financial challenges further compound the burden of childhood cancer. Treatment requires extensive healthcare resources, including medications, diagnostics, and specialized services, while long-term follow-up for relapse and secondary malignancies adds additional costs (26). NGOs have emerged as critical actors in bridging these gaps. Their independence, volunteerism, and community-focused mission allow them to address neglected areas in healthcare, provide psychosocial support, and influence policy (49). NGOs contribute to improved treatment outcomes, enhanced caregiver support, and overall public health promotion. Examples include the Mohammad Rasool Allah Charity in Yazd and the Mahak Society for Supporting Children with Cancer in Iran, which provide financial, emotional, and logistical support to pediatric cancer patients and their families (50-53).

Overall, integrating psychosocial interventions, reducing caregiver burden, and strengthening NGO involvement are essential strategies for improving survival, quality of life, and equitable access to care in pediatric oncology. Future research should continue to evaluate the impact of NGO-led initiatives, particularly in low-resource settings, and explore sustainable models for combining psychosocial support with financial and healthcare assistance

Conclusion

NGOs serve as essential actors in pediatric cancer care, bridging gaps in psychosocial support, healthcare delivery, and financial assistance. Strengthening NGO-led initiatives offers a promising strategy to improve outcomes, reduce caregiver burden, and enhance the overall quality of life for children with cancer and their families. Future research should explore sustainable models for NGO involvement, and policymakers are encouraged to integrate NGO capacities into national pediatric cancer control strategies to maximize.

Ethical Considerations

It is review article

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During the preparation of this work the author(s) did not use AI.

Author’s Contribution

Masih Ganji Ashtijeh wrote and edited the study, Iraj Hosseini Sadrabadi designed

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and supervised the study, and Abdolreza Barzegar prepared the initial draft and edited it.

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Conflict of Interest

None

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