



Original Research

Advancing the development of national childhood cancer care strategies in Latin America



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ABSTRACT

Background: Despite a rising burden of cancer among children in low- and middle-income countries (LMICs), few efforts to develop system-wide strategies to combat childhood cancer exist. Such efforts are hampered both by gaps in research evidence and by weak links among stakeholders spanning the trajectory from research and care to policy. Deliberative dialogues have emerged as a promising means of advancing evidence-informed policy, by providing a structured forum for key stakeholders to integrate and explore scientific and experiential knowledge about complex health system issues.

Methods: We convened a two-day deliberative forum with a broad array of stakeholders to collectively identify core problems, objectives, potential solutions, and key implementation considerations related to the development of national childhood cancer strategies in Latin America.

Results: from this deliberative process describe broadly endorsed elements of a solution to the challenges posed by childhood cancer in the region, both at the level of individual countries and through supra-national collaboration. Key findings include: the potential role for a pan-regional task force on childhood cancer in advancing collective goals; the import of structured health system guidance to national policy and program development on childhood cancer; and the crucial need for enhanced capacity to monitor and evaluate childhood cancer systems and policies.

Conclusion: The fruits of this deliberative process include novel policy-relevant research and advocacy endeavours, and enhanced relationships among diverse regional stakeholders to support evidence and policy development relevant to childhood cancer care in Latin America. Deliberative dialogues hold promise for advancing evidence-informed health system strategies on childhood cancer care in other LMIC contexts.

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1. Introduction

Outcomes for children with cancer in high-income countries (HICs) have improved significantly in the past several decades [1]. The same is not true for many low- and middle-income countries (LMICs), which carry 90% of the global burden of childhood

cancer [2]. As compared to 80% in HICs, survival rates from childhood cancer in LMICs range from 5 to 60%, in part due to variability in health-system capacity, political attention, and commitment within and between countries [3].

Considerable knowledge and efforts exist to address the childhood cancer burden in LMICs [4–6]. For example, a number of Latin American countries have led the development of local childhood cancer services towards improving survival rates [7–20]. However, in most cases, these advances have not been scaled up and integrated into system-wide approaches [11,12].

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Designing an evidence-informed strategy for addressing health-system issues in childhood cancer requires the creative interplay of the best available scientific evidence with the knowledge and experiences of those involved in or affected by the issue [13]. To this end, we convened a dialogue with a broad array of stakeholders to collectively identify core problems, potential solutions, and key implementation considerations related to the development of national childhood cancer strategies in Latin America.

2. Methods

We convened a two-day deliberative forum, *Placing Childhood Cancer on the Global Child Health Agenda*, at the Brocher Foundation in Hermance, Switzerland on June 8–9, 2015. An evidence brief [14] was sent to participants prior to the dialogue. Our methods for preparing the brief are outlined in Table 1 and our approach to convening the dialogue is described below.

In collaboration with the steering committee, we identified and invited health-system stakeholders (government officials, inter-governmental organizations, NGOs, leaders of professional and patient organizations, clinicians and researchers) who could: 1) bring unique views and experiences to bear on the challenge; and 2) champion within their respective constituencies actions that would address the challenge. Participants were identified by reviewing government directories, the websites of relevant organizations, extant academic literature on childhood cancer care in Latin America, key informant interviews, and through suggestions from steering committee members.

Participants received the evidence brief two weeks prior to the dialogue, and were requested to read it in advance to ensure comparable foundational knowledge and a common starting place for detailed discussion. Day 1 of the dialogue included deliberations about each section of the brief, as well as a deliberation about next steps that could be taken by different constituencies. We did not aim for consensus, in order to provide a space for free exchange of varied views and perspectives. To promote and protect such exchange, the dialogue followed the Chatham House rule: information used during the meeting could be used, but neither the identity nor the affiliation of participants were to be revealed. The dialogue was therefore not recorded, but detailed notes were taken by the facilitator and study-team members; these were used to develop a thematic analysis of the deliberations.

Day 2 of deliberations began with a summary of Day 1 deliberations, followed by dedicated discussion of discrete topic areas (early detection, treatment and care, survivorship, and monitoring, evaluation and research). For each topic of focus, participants sought to identify challenges, solutions and good practice examples from the region in the domains of health system governance, delivery and financing. Themes from the preceding stakeholder dialogue informed the discussion. Deliberations were structured by the following agenda: 1) identifying key priorities and targets; 2) applying the elements addressed in the dialogue (pan-regional task force, health system guidance, monitoring and evaluation) to advance topic-specific goals; and 3) considering the dynamics and contextual realities of appropriate integration of efforts with existing health services. As with Day 1, we used notes from facilitators and study-team members to develop a thematic analysis of the deliberations.

3. Results

We present below a summary of the key findings from the evidence brief and the major themes of the Day 1 and 2 deliberations, which included 24 participants (two policymakers, one manager, six healthcare professionals, six researchers, and nine stakeholders

from across Latin America as well as from Canada, the United States and several global health organizations). Full versions of the evidence brief and dialogue summary are available on the McMaster Health Forum website (www.mcmasterhealthforum.org) [14,18].

3.1. Key findings from the evidence brief

Key messages from the evidence brief are summarized in Tables 2 and 3. Table 2 describes the main factors contributing to the problem of childhood cancer in Latin America, while Table 3 summarizes the three identified elements of a comprehensive approach to address it: 1) a pan-regional task force, 2) health system guidance, and 3) monitoring and evaluation.

As highlighted in the evidence brief, implementing these elements will hinge on: 1) making the case that childhood cancer is not a competing policy priority, but rather one integral to reducing childhood mortality, improving health over the lifecourse and strengthening health systems; 2) building regional and national buy-in for the objectives and design of a multi-stakeholder task-force; 3) engaging national and international organizations (e.g. child and adolescent health, non-communicable diseases, and cancer-specific networks) to encourage joint action on childhood cancer policies; and 4) building capacity for health-system guidance as well as monitoring and evaluation.

3.2. Thematic summary of day 1 stakeholder dialogue

Dialogue participants broadly agreed that the problems associated with childhood cancer policy in Latin America were effectively captured through the themes presented in the evidence brief (Table 1). In-depth deliberation about these dimensions of the problem yielded insights along three further overarching themes: 1) limitations in context-specific and comparative evidence for policy and program development; 2) gaps between existing knowledge and the capacity for policy implementation; and 3) constraints on advocacy related to problem awareness and framing. Relationships between knowledge, policy and action were at the core of the problem deliberations. Notably, participants identified key weaknesses in the evidence-to-policy trajectory at junctures specific to policy development, implementation, and advocacy.

Deliberations about the three elements of a comprehensive approach to addressing the problem centred on the nature, constitution, and functions of a pan-regional task force on childhood cancer policy. Participants agreed on the potential for a pan-regional task force to enhance collective action toward addressing shared issues (e.g., building cancer registries and enhancing access to diagnosis, medicines and allied treatment) and to support distinct efforts at the national level, which would continue to be the main locus of action. They highlighted the following features as integral to task force legitimacy and success: 1) a coherent statement of purpose; 2) clearly articulated foundational values; 3) strong governance; and 4) prioritization of activities that could benefit from pan-regional scope. Participants also cautioned that regional action should strive to recognize and integrate national efforts, and not seek to supersede them.

A second major component of the discussion about solutions related to the need for an integrated approach to health-systems guidance and monitoring/evaluation. Initial divergence of views about the feasibility and legitimacy of health-systems guidance – founded on discrepant notions of evidence and varying perceptions of data availability and quality – ultimately converged around the need for better evidence, and agreed upon priorities to that end. Participants endorsed the utility of a framework to guide evidence synthesis, data collection, and health-system guidance endeavours, and stressed the intertwined nature of these facets of a solution.

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