

Storytelling workshop to encourage stakeholder engagement with the Global Initiative for Childhood Cancer

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ABSTRACT

Storytelling can enhance stakeholder engagement and support the implementation of the World Health Organization and Pan American Health Organization's (PAHO) Global Initiative for Childhood Cancer, which aims to improve care globally for children with cancer. The Initiative aligns with the United Nations Sustainable Development Goals, addressing health, education, inequalities and international collaboration. This report describes the design and implementation of a workshop that used storytelling through film to encourage stakeholders in national cancer control plans to engage with the Initiative in its focal countries in Central America, the Dominican Republic and Haiti. A six-step process was used to develop the virtual workshop hosted by PAHO: (i) define the audience; (ii) define the goals of storytelling; (iii) build an appropriate storyline, including choosing a platform and content, and addressing group dynamics and the length of the film; (iv) guide the workshop's design and implementation with current theoretical frameworks, including the Socioecological Model of Health and the Theory of Change; (v) design interactive group exercises; and (vi) disseminate workshop results. The skills-building component of the day-long workshop included 80 representatives from eight countries in the Region of the Americas, with participants representing pediatric oncology, hospital administration, ministries of health, nonprofit foundations, the scientific community and public health organizations. Outputs from the workshop included (i) a summary report, (ii) an empathy word cloud with live reactions from participants, (iii) qualitative responses (i.e. quotes from participants), (iv) stakeholders' analyses and (v) a prioritization matrix for country-level strategic activities that could be undertaken to strengthen health systems when caring for children with cancer. The workshop used storytelling through film to try to reduce health inequalities and have a regional impact. Combining art, public health and medicine, the workshop created positive change by sharing real-life experiences. Commitment was fostered among stakeholders through their engagement with the workshop, which aimed to increase their awareness of the need and advocacy to improve health systems and enhance access to health care for this vulnerable population.

Keywords

Adolescent health; child health; health communication; neoplasms; disease prevention; health systems.

Storytelling has frequently highlighted health disparities and mobilized awareness for critical global public health issues. This study explores how compelling storytelling can be a valuable

tool for encouraging stakeholder engagement and advocacy (1) to strengthen the implementation of the World Health Organization (WHO) and Pan American Health Organization's (PAHO)

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Global Initiative for Childhood Cancer, which aims to improve cancer care for children and adolescents worldwide, regardless of their country, race or gender, and is closely aligned with the United Nations (UN) Sustainable Development Goals (SDGs) for the year 2030, particularly in terms of health, education, the reduction of inequalities and encouragement of international collaboration.

Stakeholder engagement is meaningfully involving persons affected by research findings or programs in any key process (2). It is recognized as pivotal to improve how public health interventions are prioritized, translated and used in real-life settings (3).

In health care, storytelling design incorporates patients' and families' experiences to promote and develop interventions. True-to-life films empathically observe and honor multiple perspectives, and allow viewers to evaluate the interactions of leading characters over time. Health care films require intentional design to maintain confidentiality when using video-based data (4).

Using film to tell stories is an effective way to directly share interactions and emotions, making it easier to disseminate content to various stakeholders, such as clinicians, members of civil society organizations and policy-makers. Story-based films aim to authentically convey practical experiences to a wider audience, serving as an advocacy and engagement tool for health care teams (5).

This paper outlines the storytelling strategy used to design and implement a PAHO workshop using the film titled, *How I live*. The workshop aimed to engage stakeholders in implementing national cancer control plans for Central America, the Dominican Republic and Haiti to promote long-term health system strengthening to improve care for children with cancer.

BACKGROUND

The gap in childhood cancer care

Latin America faces severe burdens from childhood cancer morbidity and mortality. Access to care for childhood cancer

is inconsistent and limited, with significant differences in outcomes within and between countries because of inequities in access to diagnosis and treatment. Latin America needs more cohesive policies and practices to strengthen the control of childhood cancer, which is integral to enhancing child health and fortifying health systems. Childhood cancer receives limited attention from policy-makers despite its importance in reducing childhood mortality and improving health over the life course (6-8).

WHO, St. Jude Children's Research Hospital and global partners launched the WHO Global Initiative for Childhood Cancer at the September 2018 UN General Assembly. This Initiative aims to achieve a minimum 60% global survival for children with cancer while reducing suffering for each child (9).

International collaboration to accelerate implementation of the Initiative

Strengthening the health system to improve cancer care for children and adolescents is a priority of the SDGs. Thus, convening a regional task force with national working groups to develop and oversee national childhood cancer strategies in Latin America is a public health priority. PAHO and WHO, along with international institutions, St. Jude Children's Research Hospital, the Harvard Humanitarian Initiative and Persistent Productions, a film production company specializing in storytelling for social impact, designed a strategy to promote regional dialogue through workshops. The aim was to advocate for children and adolescents with cancer by helping low- and middle-income countries (LMICs) build their capacity for continual care.

Strategy development

A six-step process was developed to strategize and implement the PAHO workshop (10), which was delivered virtually owing to constraints of the COVID-19 pandemic. The steps included (i) defining the audience, by country and type of institutions, and by the positions and backgrounds of health

TABLE 1. Profile of participants in the *How I live* workshop, 2021







Representatives from	No. of participants	Affiliation
Countries	8	 Costa Rica, Dominican Republic, El Salvador, Guatemala, Haiti, Honduras, Nicaragua and Panama
Ministries of health	14	 Unit for Chronic Noncommunicable Diseases; Comprehensive Care Unit for Women, Children and Adolescents.
Members of Childhood Cancer Committees	24	 Pediatric oncologists, hospital administrators and stakeholders working at the national level in pediatric cancer control, including directors of hospitals and nonprofit foundations
Focal points at the Pan American Health Organization	18	 National and subregional officials and local consultants
Key stakeholders at the regional level	2	 Members of the Executive Secretariat of the Council of Ministers of Health of Central America and the Dominican Republic
International scientific experts and technicians working in childhood cancer control	14	 Pan American Health Organization, Washington, D.C.; St. Jude Children's Research Hospital; Harvard Humanitarian Initiative; Persistent Productions

FIGURE 1. Steps in the design and implementation of the *How I live* workshop, including preworkshop tasks, 2021^a

CCC: Childhood Cancer Committee.

^a The preworkshop tasks were designed to help participants learn about the importance of stakeholder engagement in childhood cancer care, emotionally connect with the stories in the *How I live* film, and identify barriers and facilitators to improving care for children with cancer in their country.

care and policy-maker professionals; (ii) defining the goals of storytelling, which are to emotionally engage participants and provide them with a compelling action toolkit; (iii) building an appropriate storyline, in terms of platform, content, group dynamics and length of the film; (iv) guiding the workshop's design and implementation with current theoretical frameworks, including the Theory of Change, Socioecological Model

of Health, the CureAll framework, WHO's Global Initiative for Childhood Cancer, the SDGs and WHO's Health Systems Building Blocks; (v) designing interactive group exercises; and (vi) disseminating the results of the workshop.

Defining the audience. Under the leadership of its 52 member countries and territories, PAHO sets regional health priorities

TABLE 2. Program for the *How I live* workshop, 2021

Session one: introduction (1 h and 30 min)	
Opening ceremony	10 min
Welcoming remarks	10 min
<i>How I live</i> : clip from the film and a call to action	10 min
Introduction to the film as a catalyst for public health action and policy change	10 min
An update about the implementation plan for the Global Initiative for Childhood Cancer in Latin America, what has happened since the United Nations General Assembly in 2018; case experiences in El Salvador (advocacy), Guatemala (health care team engagement), Peru (health system pediatric cancer policy)	10 min
Harnessing emotional empathy from the film: together we can change how children live with cancer in our countries (short activity: empathy mapping)	10 min
Overview of the Pan American Health Organization/World Health Organization Global Initiative for Childhood Cancer and CureAll framework in the Region of the Americas	15 min
St. Jude Global Pediatric Medicine and the development of the national pediatric cancer plan in Central America, the Dominican Republic and Haiti as part of the Initiative	15 min
Session two: skills-building exercises (3 h and 30 min)	
Exercise one: Prioritizing strategic activities across the health system according to their value, referring to what individuals and societies deem as desirable ways of living, and the political will, referring to the commitment of political leaders to achieve certain goals and bear the associated costs over time	
Introduction and overview of the exercise	5 min
Steps to develop a value and political will matrix for national 2-year activities within national pediatric cancer plans and the Regional Strategy for Childhood Cancer of the Executive Secretariat of the Council of Ministers of Health of Central America and the Dominican Republic	15 min
Breakout session for national experts, by country	5 min
Developing the value and political will matrix using the prioritized activities within national pediatric cancer plans and the Regional Strategy for Childhood Cancer of the Executive Secretariat of the Council of Ministers of Health of Central America and the Dominican Republic	50 min
Country outputs discussion	30 min
Exercise two: stakeholder analysis	
Introduction and steps to develop a stakeholder analysis table and matrix	15 min
Breakout session for national experts, by country	5 min
Developing a stakeholder analysis table and matrix	50 min
Country outputs discussion	30 min
Closing: next steps	5 min

and mobilizes actions to address health problems that respect no borders and, in many cases, jeopardize health systems' sustainability.

The intended audience for the *How I live* film and virtual workshop comprises ministries of health, pediatric oncology specialists, nonprofit organizations (e.g. childhood cancer foundations), hospital directors and PAHO consultants. Dissemination of the event was carried out in close collaboration with the PAHO country officers. Table 1 summarizes the affiliations and numbers of participants in session two.

Define storytelling and its goal. In the context of health information, storytelling can humanize complex medical concepts and processes, making them more relatable and understandable. Additionally, stories can evoke emotions that may contribute to persuasion, a crucial aspect in interventions seeking to change health behavior. The team of organizers was guided by visual media's increasing prevalence and influence in today's digital age. As a visual storytelling approach, a film can be far-reaching, and it allows for the inclusion of elements such as body language, tone of voice and visual cues, which can greatly enhance the delivery and reception of the intended health message (1).

Persistent Productions' film *How I live* was selected for the workshop, given the increasing attention to storytelling as a potentially adaptable stakeholder engagement approach that is especially relevant to populations with health disparities, such as in Latin America and the Caribbean, for whom there is a strong cultural connection to storytelling as a form of social

discourse (11). Additionally, two of the four children in the film were from countries taking part in the regional workshop in Central America. The film debuted during the launch of the Global Initiative for Childhood Cancer on September 27, 2018, at the UN General Assembly.

The production company spent 4 years filming interviews with and footage from health care teams familiar with the challenges faced by families of children with cancer. These health professionals work to provide quality care under adverse conditions. The stories from the front lines of global pediatric oncology in four LMICs – Egypt, El Salvador, Guatemala and Myanmar – show the power of parents' love, children's courage and what is possible when a community is dedicated to treating and someday curing childhood cancer (12).

The organizers of the virtual workshop chose to use the film to emotionally connect and engage with important stakeholders in childhood cancer care and guide them towards implementing national pediatric cancer control plans as part of the WHO Global Initiative for Childhood Cancer and the CureAll framework. The goal of the workshop organizers was to help stakeholders relate to the complex issues facing patients, families and health care providers, from diagnosis through treatment, through the film. The film documents the difficulties not only of cancer treatment but also the physical and geographical obstacles to accessing care and how these can be the most daunting to overcome.

Building an appropriate storyline: platform, content, group dynamics and film length. The planning process started in

SDGs as a framework to analyze key themes illustrated in the film. Overviews of the Global Initiative for Childhood Cancer and the *CureAll* Framework were also presented, and the role of the St. Jude Global Pediatric Medicine Team in developing the national pediatric cancer plan in Central America, the Dominican Republic and Haiti, as part of the WHO/PAHO Initiative, was also discussed (14).

Session two. During this session, the same group of experts facilitated skills-building exercises. Participants were divided into eight breakout groups organized by country. The session focused on two main exercises: (i) prioritizing strategic activities across the health system according to their value and the political will for implementation and (ii) developing a stakeholder analysis.

Session two aimed to equip participants with two specific skills: first, learning how to use the St. Jude Children's Research Hospital Health System Unit's Childhood Cancer Control Country Collaboration tool (C5) to identify progress, priorities, challenges, gaps and potential stakeholders within the continuum of the WHO/PAHO Initiative. This tool is based on WHO's six Health Systems Building Blocks framework, adapted for children with cancer (15). The second aim was to teach participants how to use storytelling skills to collaborate as advocates for care for children with cancer and for members of the health care team, thus encouraging stakeholders to hold meetings to implement their prioritized strategic actions.

Data collection and analysis

The preworkshop survey included six open-ended questions; each participant responded with short answers. The goals of this survey were to characterize participants' reactions and collect content for the workshop process.

The skills-building exercises were evaluated using qualitative methods, with field notes taken during the breakout sessions. Each breakout group had two facilitators. Facilitators included eight notetakers from the PAHO team, two members of the Executive Secretariat of the Council of Ministers of Health of Central America and the Dominican Republic, one representative from the Harvard Humanitarian Initiative and five from St. Jude.

Descriptive analysis was used to examine participants' characteristics and responses, and response rates to the surveys administered before the workshop were also calculated. Descriptive analyses used the word cloud for an empathy mapping exercise that elucidated participants' perceptions regarding the multifaceted challenges faced by patients and their caregivers in accessing care for childhood cancer, as well as the challenges faced by physicians. Utilizing a range of metrics, including frequency distributions and thematic categorizations, the empathy map served as a visualization of qualitative data that encapsulated sentiments and barriers, thereby offering a nuanced understanding of stakeholders' experiences. In a complementary approach, the workshop also incorporated the C5 Tool section matrix of value and political will (designated as

TABLE 3. Stakeholder analysis and 2-year prioritized activities based on their value and the political will to achieve them (c2, c4, c5) (14) from the *How I live* workshop, 2021^a

Country	C2 stakeholders	C4 key area	C5 prioritized activity
Costa Rica	Ministry of Public Education, National Children's Trust	Health service delivery	Develop national cancer plan, including a comprehensive approach to six index cancers
Dominican Republic	Society of Pediatricians, Society of Hematology, Ministry of Public Health, PAHO, National Health Service	Health workforce	Develop training on factors affecting childhood cancer survival
El Salvador	Childhood and Adolescence Unit of the Ministry of Public Health, Directorate of Hospitals, Directorate of Primary Health Care, Fundación Ayúdame a Vivir	Health service delivery	Design early diagnosis and referral program
Guatemala	Ministries of Public Health and Finance, Congress	Governance and financing	Increase state budget for childhood cancer strategic interventions
Haiti	Ministry of Public Health, Fondation Haitienne Anti-Cancer Infantile (Haitian Foundation Fighting Childhood Cancer)	Information systems	Organize national cancer registry
Honduras	Ministry of Public Health, General Directorate of Health Services Networks at the primary health care level, Human Resources Directorate	Health service delivery	Implement early detection workshops for personnel working in primary health care
Nicaragua	Ministry of Public Health, National University, Social Security	Health workforce	Establish continuing education program based on WHO's Integrated Management of Childhood Illness approach
Panama	Childhood and Adolescence Program at the Ministry of Public Health, National Association of Nurses, Society of Pediatrics	Health workforce	Develop early detection and timely care course for the PAHO Public Health Virtual Campus, Panama node

PAHO: Pan American Health Organization; WHO World Health Organization.

^a Table 3 shows stakeholders, analyses and themes from the regional and national workshops. The designations c2, c4 and c5 refer to the St. Jude Children's Research Hospital Health System Unit's Childhood Cancer Control Country Collaboration tool, known as the C5 Tool; specifically c2 refers to mapping the roles of institutions and organizations, collecting information about relevant stakeholders (e.g. hospitals or other service delivery centers, ministries of health, nonprofit foundations). Using this information, the organizers were able to work with teams to develop a structured country summary map and define other stakeholder mapping outputs. The designation c4 refers creating matrices for key health system areas, which helps teams to prioritize broader areas for potential collaboration, based on data from other sections of the C5 Tool. Team members also assessed the time needed for each key area identified, which will inform further prioritization in the following section. The designation c5 refers establishing priority collaborative portfolios, which assists teams in further narrowing their areas of collaboration to focus on specific projects that can be achieved in the near- and long-term, including considering a project's value and the existing political will. Additionally, teams identified the resources needed to complete the prioritized projects. These examples are illustrative only and not exhaustive; they do not represent the spectrum of discussions and exercises engaged in by participants.

Source: Table adapted from reference (14).

c5) (see additional details in the Results section). This matrix uses a two-dimensional framework, categorizing strategic initiatives on axes of value (i.e. impact on health care outcomes) and political will (i.e. feasibility and stakeholder support). The c5 matrix effectively prioritizes activities by generating a quantifiable representation of where interventions stand in terms of potential impact and ease of implementation, thereby informing actionable steps for improving access to childhood cancer care. Both analytical tools collectively provided a comprehensive, data-informed view that is pivotal for designing targeted interventions.

RESULTS

The 5-hour workshop was held in two sessions on August 13, 2021, virtually over the Zoom platform, with translation from Spanish to English and French.

Outputs of the workshop included: (i) a summary report, (ii) an empathy word cloud with live reactions from the participants, (iii) qualitative responses (i.e. quotes from participants), (iv) a prioritization matrix for strategic activities at the country level and (v) a stakeholder analysis.

Responses to session one

The first session lasted for 1 hour and 30 minutes and was open to the public. A total of 150 participants from 25 different countries took part. Altogether, 131 responded to the empathy mapping survey statement in which they were instructed to, “Please type 1–3 words representing how you felt after watching the film”; the response rate was 87% (130/150). The word cloud developed from participants’ reaction showed that their most common feelings were “engaged” (comprometida), “emotional” (emocionada), “shocked” (impresionada) and “hopeful” (esperanzada) (Figure 2).

Only 81 participants (54% response rate) responded to the open-ended qualitative questions in workshop session one. When asked about the difference between learning about global childhood cancer from a film compared with in a scientific journal or newsletter, all respondents emphasized the impact of real people’s stories on their understanding of the global burden of childhood cancer. One representative quote expresses this sentiment:

The difference is that the film makes it easy to instantly convey clear concepts such as cancer in children and adolescents as true to life. It can affect any age group between 0 and 19 years, regardless of the person’s socioeconomic status. By projecting real stories, the storytelling reaches the sensitive part of the human being. It makes the audience reflect on how vulnerable any human being is when diagnosed with cancer, turning the scientific journals’ concepts and statistics [and] data on childhood cancer disparities and survival gaps in low- and middle-income countries compared with high-income countries into faces, names, lives and countries, allowing the audience to create an awareness framework for the topic that promotes a call to action and empowers health care providers.

When asked about the barriers and facilitators to accessing care for childhood cancer depicted in the film and whether they

reflect a participant’s reality in their own country, 56% (45/80) recognized geographical distance to specialized health care centers and the socioeconomic status of families as barriers, 33% (50/150) mentioned a lack of access to essential medicines for childhood cancer and diagnostic technology, and 22% (33/150) highlighted the absence of a workforce trained to deliver care for childhood cancer.

When asked whether the facilitating factors identified in the film related to their own country’s reality, 44% (66/150) of respondents described the presence of nonprofit civil society organizations (i.e. foundations) involved in the direct care of children and adolescents with cancer, 33% (50/150) identified government-provided universal coverage packages for childhood cancer and 23% (35/150) identified the presence of health systems networks and community engagement.

Workshop session one ended with participants commenting in the Zoom chat about their favorable experiences while watching the film, expressing that they had learned storytelling could be a tool to communicate with and help others to understand their scope of work. Several participants wrote about their plans for using storytelling as a tool to engage stakeholders and as a method for disseminating their research to target communities.

Responses to session two

A total of 80 people participated in the skills-building exercises, which is an attendance rate of 53% (80/150). Altogether 31% (25) of participants represented ministries of health, 30% (24) represented public health organizations, 14% (11) represented pediatric oncology hospital administrations, 14% (11) represented nonprofit foundations and 11% (9) represented the scientific community.

Following a series of childhood cancer workshops and regional dialogues in 2019, Central American countries, the Dominican Republic and Haiti recognized the need to develop national childhood cancer control plans. PAHO and its collaborators – the St. Jude Global Pediatric Medicine Team, Persistent Productions and the Harvard Humanitarian Initiative – planned and organized session two to support the eight countries in implementing national and regional cancer control initiatives. Countries achieved this goal using St. Jude Children’s Research Hospital’s C5 Tool, which is a participatory mapping tool designed to aid in decision-making in health care systems, with a focus on facilitating collaboration and strategic planning. It consists of five sections: c1, evaluating national indicators; c2, mapping roles of institutions and organizations; c3, conducting a national analysis of strengths, weaknesses, opportunities and threats (or SWOT); c4, creating matrices for key health system areas; and c5, establishing priority collaborative portfolios. These sessions enable teams to identify short-term and long-term collaborative projects based on their value and the political will to implement them. The workshop used c2, c4 and c5 to define 10 priorities, rank them according to their value, which is context specific and varies across national prevention programs for cancer by country, and refers to societal or individual desirability. The political will component signifies whether there is sustained commitment from leaders to achieve specific objectives. The C5 Tool produces actionable outputs for national programs and strategic planning by prioritizing initiatives based on these two criteria. It accommodates the

perspectives of various stakeholders, such as the values held by patients, families, health care providers, policy-makers and funding agencies, thereby fostering a comprehensive, multidimensional approach to health care improvement.

For each prioritized action outcome ranked according to WHO's six Health Systems Building Blocks, each country sought to formulate results for which it has the mandate and comparative advantage to implement, by identifying several *CureAll*-based outputs that require the leadership of the country's Childhood Cancer Committee and its contribution to outcome-level change. For instance, if a country prioritizes the outcome of providing high-impact health care to all children and adolescents with cancer, especially those living in vulnerable conditions, the country could focus on the following strategies: accelerating scale up of the essential package of universal health coverage, implementing centers of excellence for early childhood cancer diagnosis and ensuring access to essential medicines and technology for diagnosis. By taking these actions, all children and adolescents with cancer, particularly those in vulnerable conditions, can survive and thrive within their communities.

Each country selected a strategic activity for phased implementation to span an overlapping period of 2 calendar years, 2022 and 2023 (Table 3), and utilized storytelling to share insights with other teams and involved stakeholders. After the workshop, country teams continued to implement action plans. To ensure robust oversight and continual improvement, regional and country teams involved in the Global Initiative for Childhood Cancer engage in monthly progress meetings with key stakeholders, including PAHO and the team from St. Jude's, as well as collaborating entities across Latin American and Caribbean nations. These interactive sessions serve as a platform for data-driven dialogue and evidence-based adjustment of strategies. Personalized technical assistance is also provided by PAHO and the St. Jude's team upon request, and aims at resolving unique challenges and optimizing implementation processes. The post-workshop report generated from these meetings offers a comprehensive guide, replete with methodological insights designed to facilitate replication of the workshop in different settings, be it in other PAHO or WHO regional offices, other countries or other hospital systems. This report serves as a knowledge transfer mechanism, with participants sharing actionable insights, lessons learned and targeted action plans aimed at incorporating storytelling techniques into their respective health care environments.

Additionally, the workshop's outputs have helped prioritize cancer control strategies in national pediatric cancer plans and support the Initiative's activities, and development of key documents, such as those about resource mobilization and national and regional cooperation strategies.

Two weeks after the workshop, organizers shared meeting notes and recordings with the participants, along with the potential next steps to be taken. Childhood Cancer Committees are collaborating with the Regional Office for the Americas, PAHO country focal points and the St. Jude Children's Research Hospital's Global Pediatric Medicine Team to address the action points.

DISCUSSION

The *How I live* film and virtual workshop were designed to engage participants in a discussion prompted by the film and

guide health care stakeholders' understanding of the health information conveyed.

Benham Asl et al. have stated that digital storytelling can be used as an effective way to securely share interactions and emotions directly from videos so that their content can be disseminated to researchers, clinicians, participants and policy-makers (1). Therefore, to leverage the growing emphasis and relevance of intentional stakeholder engagement, the organizers successfully developed and implemented an interactive workshop using storytelling through film to engage key stakeholders and build momentum for sustainable capacity-building in global childhood cancer care.

Based on the study by Brooks et al. (16), systematic reviews indicate that storytelling can influence positive changes in health-related behaviors. Utilizing storytelling as a method for knowledge translation is complex and demands meticulous planning, taking into account various factors. Considering these data, the organizers used a two-session structure for the workshop (i.e. an introductory session followed by skills-building exercises with interactive breakout groups) that provided participants first with a general overview about using compelling narratives, followed by an opportunity to practice the art of storytelling.

Forsythe et al. (3) discussed the use of a self-report instrument to highlight varying levels of engagement, ranging from consultation to collaboration, in bidirectional partnerships with researchers and even to stakeholder-directed projects. In this context, the authors emphasized the significance of continuing partnerships, strategic selection of stakeholders and the accommodation of stakeholders' needs as crucial lessons. Similarly, from the perspective of the workshop's organizers and participants, several key takeaways were identified as lessons learned.

The organizers and participants recognized that storytelling allowed childhood cancer experts to reflect upon and craft a personal message to enable stakeholders to connect emotionally with the challenges faced by children with cancer, their family and health care providers throughout the treatment process.

A heartfelt narrative is pivotal to stakeholders building networked alliances to identify and understand how to tackle the disparities in childhood cancer that exist between LMICs and HICs. Participants indicated that the *How I live* film possesses the ability to transform statistics into relatable stories, galvanize collective action and, ultimately, catalyze meaningful change, fostering collaboration in the realm of childhood cancer care.

Participants and organizers described storytelling as a tool that can be used to engage stakeholders in childhood cancer care to increase their awareness and open a national or regional dialogue to serve as a springboard for the Theory of Change processes of reflection and insight, and to prioritize a cancer-specific call to action by identifying the barriers and facilitators to improving health care access for children and adolescents with cancer, thus reducing their suffering and improving their survivorship. After the workshop, the organizers held a conference call to discuss and assist with collaborative problem analysis and strategy development.

Virtual workshops have limitations, such as the limited time between sessions during a 5-hour program. Because of these concerns, it may be better to divide the workshop into 2 days. Another concern is the time-consuming follow up required for the prioritization activities and to develop outputs from the eight countries' groups. The organizers, who specialize in

planning for childhood cancer control, will guide and support the Childhood Cancer Committees in their decision-making and implementation of strategies.

Despite the workshop's positive impact, some participants reported uncertainty about the preworkshop tasks and framing their stakeholders' stories. For future iterations, the organizers will spend more time reviewing the story development process and provide explicit instructions to improve participants' understanding of each activity's aims.

In conclusion, these findings are consistent with those of Al-Huneidi and Schreurs (17), who reported that storytelling generated strong emotional engagement among audiences working in higher education while allowing them to maintain high levels of attention and interest. The organizers noted a regional learning process occurring among countries that fostered increased communication and collaboration among Childhood Cancer Committees. Following a national-level workshop by Panama's Childhood Cancer Committee, which used storytelling to advance the prioritization of strategic activities for their pediatric cancer control plan, Costa Rica conducted 3 days of workshops. These workshops utilized storytelling to engage stakeholders, conduct a situational analysis of childhood cancer, prepare the planning process for childhood cancer control, identify childhood cancer control as a health priority, establish a nodal officer and form a technical working group with national and international experts.

The initial workshop not only intended to disseminate information but also to provoke thought and stimulate conversation, making the information more relatable and memorable and facilitating the implementation of sustainable strategies to improve health systems to care for children with cancer at the regional level.

Authors' contributions. SFA, KC, IA and MS conceptualized the core idea of the study; designed the first workshop

session; undertook comprehensive data collection, analysis and interpretation; and drafted the manuscript. SFA and LV spearheaded the design and conceptualization of the second workshop session. All authors, including SL, MM and SBM, provided input into the design and content of the workshops, and critically reviewed and approved the final version of the manuscript.

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REFERENCES

1. Benham Asl S, Gill C, Umstead K, Mahtani R, Tully K. A collaborative approach to digital storytelling in healthcare settings [Internet]. In: Bohemia E, Buck L, Grierson H, editors. DS 117: Proceedings of the 24th International Conference on Engineering and Product Design Education. Glasgow: Design Society; 2022 [cited 2022 September 8]. Available from: <https://www.designsociety.org/publication/45888/A+COLLABORATIVE+APPROACH+TO+DIGITAL+STORYTELLING+IN+HEALTHCARE+SETTINGS>
2. Joosten YA, Israel TL, Williams NA, Boone LR, Schlundt DG, Mouton CP, et al. Community engagement studios: a structured approach to obtaining meaningful input from stakeholders to inform research. *Acad Med.* 2015;90:1646-50.
3. Forsythe LP, Ellis LE, Edmundson L, Sabharwal R, Rein A, Konopka K, Frank L. Patient and stakeholder engagement in the PCORI pilot projects: description and lessons learned. *J Gen Intern Med.* 2016;31:13-21.
4. Asan O, Montague E. Using video-based observation research methods in primary care health encounters to evaluate complex interactions. *Inform Prim Care.* 2014;21:161-70.
5. Lipsey AF, Waterman AD, Wood EH, Balliet W. Evaluation of first-person storytelling on changing health-related attitudes, knowledge, behaviors, and outcomes: a scoping review. *Pat Educ Couns.* 2020;103:1922-34.
6. Gavidia R, Fuentes SL, Vasquez R, Bonilla M, Ethier MC, Diorio C, et al. Low socioeconomic status is associated with prolonged times to assessment and treatment, sepsis and infectious death in pediatric fever in El Salvador. *PLoS One.* 2012;7:e43639.
7. Rodriguez-Galindo C, Friedrich P, Morrissey L, Frazier L. Global challenges in pediatric oncology. *Curr Opin Pediatr.* 2013;25:3-15.
8. Lam CG, Howard SC, Bouffet E, Pritchard-Jones K. Science and health for all children with cancer. *Science.* 2019;363:1182-6.
9. World Health Organization. *CureAll* framework: WHO Global Initiative for Childhood Cancer: increasing access, advancing quality, saving lives. Geneva: World Health Organization; 2021. <https://apps.who.int/iris/handle/10665/347370>
10. Pan American Health Organization. Workshop "How I live" –13 August 2021 [Internet]. Washington (DC): Pan American Health Organization; 2021 [cited 2022 August 13]. Available from: <https://www.paho.org/en/topics/childhood-and-adolescence-cancer/workshop-how-i-live-13-august-2021>
11. Ballard AM, Davis A, Hoffner CA. The impact of health narratives on persuasion in African American women: a systematic review and meta-analysis. *Health Commun.* 2021;36:560-71.
12. www.howilivewithcancer.com [Internet]. Rockport (MA): How I live; 2023 [cited 2023 May 24]. Available from: <https://www.howilivewithcancer.com/>
13. United Nations Children's Fund (UNICEF). Theory of change paper, UNICEF strategic plan, 2018–2021: realizing the rights of every child, especially the most disadvantaged. New York: UNICEF; 2017 [cited 2023 May 24]. Available from: <https://www.unicef.org/strategy>

- unicef.org/executiveboard/media/1471/file/2017-EB11-Theory_of_Change-EN-2017.07.19.pdf
14. Lam CG, Vasquez L, Loggetto P, Fuentes-Alabi S, Gonzalez Ruiz A, Benitez Majano S, et al. Partnering to implement the Global Initiative for Childhood Cancer in the Americas: prioritizing systems strengthening. *Rev Panam Salud Publica*. 2023;47:e41.
 15. Mounier-Jack S, Griffiths UK, Closser S, Burchett H, Marchal B. Measuring the health systems impact of disease control programs: a critical reflection on the WHO building blocks framework. *BMC Public Health*. 2014;14:278.
 16. Brooks SP, Zimmermann GL, Lang M, Scott SD, Thomson D, Wilkes G, Hartling L. A framework to guide storytelling as a knowledge translation intervention for health-promoting behavior change. *Implement Sci Commun*. 2022;3:35
 17. Al-Huneidi A, Schreurs J. Constructivism-based blended learning in higher education. In: Lytas RD, Tennyson RD, Ordonez de Pablos P, García Peñalvo FJ, Rusu L, editors. *Information systems, e-learning, and knowledge management research: WSKS 2011*. Berlin: Springer; 2013.

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Taller de narrativa para fomentar la participación de las partes interesadas en la Iniciativa Mundial contra el Cáncer Infantil

RESUMEN

La narración de historias puede mejorar la participación de las partes interesadas y brindar apoyo para la aplicación de la Iniciativa Mundial contra el Cáncer Infantil de la Organización Mundial de la Salud y la Organización Panamericana de la Salud (OPS), dirigida a mejorar la atención a los pacientes pediátricos con cáncer en todo el mundo. La Iniciativa se enmarca en el contexto de los Objetivos de Desarrollo Sostenible de las Naciones Unidas, que abordan la salud, la educación, las desigualdades y la colaboración internacional. En este informe se describe el diseño y la realización de un taller en el que se utilizó la narración de historias mediante películas para animar a las partes interesadas de los planes nacionales de control del cáncer a colaborar con la iniciativa en los países del proyecto en Centroamérica, Haití y República Dominicana. Para preparar el taller virtual organizado por la OPS, se utilizó un proceso de seis pasos: *i)* definir el público destinatario; *ii)* definir los objetivos de la narración; *iii)* confeccionar una estructura argumental adecuada, incluida la elección del tipo de plataforma y el contenido, y tener en cuenta tanto las dinámicas de grupo como la duración de la película; *iv)* basar el diseño y la realización del taller en marcos teóricos actuales, incluidos el modelo socioecológico de la salud y la teoría del cambio; *v)* diseñar ejercicios grupales interactivos; y *vi)* difundir los resultados del taller. En el componente de adquisición de competencias del taller, de un día de duración, participaron 80 representantes de ocho países de la Región de las Américas, pertenecientes a los ámbitos de la oncología pediátrica, la gestión hospitalaria, los ministerios de salud, fundaciones sin ánimo de lucro, la comunidad científica y organizaciones de salud pública. Los resultados del taller incluyeron *i)* un resumen del informe, *ii)* una nube de palabras relacionadas con la empatía que recogía las reacciones en tiempo real de las personas participantes, *iii)* respuestas cualitativas (es decir, citas de lo expresado por las personas participantes), *iv)* análisis de las partes interesadas y *v)* una matriz de priorización de las actividades estratégicas a nivel de país que se podrían llevar a cabo para fortalecer los sistemas de salud a la hora de prestar atención de salud a los pacientes pediátricos con cáncer. En el taller se recurrió a la narración de historias en forma de película para tratar de reducir las inequidades en materia de salud y lograr un impacto a nivel regional. La combinación de arte, salud pública y medicina propició la generación de cambios favorables mediante el intercambio de experiencias de la vida real. Se fomentó el compromiso de las partes interesadas a través de su participación en el taller, lo cual tenía como objetivo aumentar su concientización sobre la importancia de la promoción y la necesidad de mejorar tanto los sistemas de salud como el acceso a la atención de salud para esta población vulnerable.

Palabras clave

Salud del adolescente; salud infantil; comunicación en salud; neoplasias; prevención de enfermedades; sistemas de salud.

Oficina de histórias para incentivar o envolvimento das partes interessadas na Iniciativa Global para o Câncer Infantil

RESUMO

A narração de histórias pode aumentar o envolvimento das partes interessadas e apoiar a implementação da Iniciativa Global para o Câncer Infantil da Organização Mundial da Saúde e da Organização Pan-Americana da Saúde (OPAS), que visa a melhorar o atendimento a crianças com câncer em âmbito mundial. A Iniciativa está alinhada com os Objetivos de Desenvolvimento Sustentável das Nações Unidas, abordando saúde, educação, desigualdades e colaboração internacional. Este relatório descreve a elaboração e implementação de uma oficina que usou histórias narradas por meio de filmes para incentivar as partes interessadas nos planos nacionais de controle do câncer a se envolverem na Iniciativa em países focais na América Central, além da República Dominicana e do Haiti. Um processo em seis etapas foi usado para desenvolver a oficina virtual organizada pela OPAS: *a)* definir o público; *b)* definir os objetivos da narrativa; *c)* construir um enredo apropriado, com consideração para a escolha de plataforma e do conteúdo, a dinâmica do grupo e a duração do filme; *d)* orientar a elaboração e implementação da oficina no âmbito de marcos teóricos atuais, como o Modelo Socioecológico de Saúde e a Teoria da Mudança; *e)* preparar exercícios interativos em grupo; e *f)* disseminar os resultados da oficina. O componente de desenvolvimento de habilidades da oficina de um dia incluiu 80 representantes de oito países da Região das Américas, com participantes representando oncologia pediátrica, administração hospitalar, ministérios da saúde, fundações sem fins lucrativos, a comunidade científica e organizações de saúde pública. Os resultados da oficina incluíram: *a)* um relatório resumido; *b)* uma nuvem de palavras de empatia com reações ao vivo dos participantes; *c)* respostas qualitativas (ou seja, falas dos participantes); *d)* análises das partes interessadas; e *e)* uma matriz de priorização para atividades estratégicas nacionais que poderiam ser realizadas para fortalecer os sistemas de saúde no cuidado de crianças com câncer. A oficina usou histórias narradas por meio de filmes para tentar reduzir as desigualdades de saúde e alcançar um impacto regional. Combinando arte, saúde pública e medicina, a oficina criou uma mudança positiva por meio do compartilhamento de experiências da vida real. A participação na oficina, cujo objetivo era aumentar a conscientização sobre a necessidade de pleitear melhorias nos sistemas de saúde e no acesso à atenção à saúde para essa população vulnerável, fomentou o compromisso entre as partes interessadas.

Palavras-chave

Saúde do adolescente; saúde da criança; comunicação em saúde; neoplasias; prevenção de doenças; sistemas de saúde.