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### Community Resources Supporting Adherence to Treatment Appointments Reduce Abandonment of Treatment In Childhood Cancer In El Salvador

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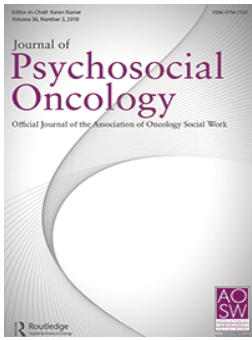
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ARTICLE

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## Community resources support adherence to treatment for childhood cancer in El Salvador

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### ABSTRACT

**Objective:** In order to reduce nonadherence and treatment abandonment of children with cancer in El Salvador, institutions located nearby the patients' homes were involved to provide support. **Methodological approach:** Health clinics and municipality offices in the patients' communities were asked to assist families who were not promptly located after missing hospital appointments, or those whose financial limitations were likely to impede continuation of treatment. Data was collected about the number of contacted institutions, the nature of help provided, staff's time investments, and parents' perceptions about the intervention. **Findings:** Local institutions (133 from 206 contacts) conducted home visits (83), and/or provided parents with money (55) or transportation (60). Parents found this support essential for continuing the treatment but they also encountered challenges regarding local institutions' inconsistencies. Nonadherence and abandonment decreased. **Implications:** Economic burden was reduced on both the families and the hospital. Involvement of external institutions might become regular practice to support families of children with cancer.

### KEYWORDS

abandonment of treatment; adherence; childhood cancer; community resources; developing countries; parents experiences

## Background

Nonadherence to treatment is defined as an inadequate intake of prescribed medication or intermittent attendance at medical appointments, and this may affect cancer therapy outcomes by lowering the treatment efficacy and increasing the risk of relapse (Butow et al., 2010). In low- and middle-income countries (LMIC),

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treatment abandonment is a significant cause of failure of childhood cancer treatment (Arora, Eden, & Pizer, 2007; Howard, Pedrosa, & Lins, 2004; Spinetta, Masera, & Eden, 2002) and can be considered an extreme form of nonadherence (Sitaresmi, 2009). Both nonadherence and treatment abandonment need to be addressed for children with cancer in less advantaged settings.

Based on a systematic review (Gupta, Yeh, & Martiniuk, 2013), the magnitude of reported abandonment varies widely, as much as from 0% to 74%, and interventions to reduce it have not been systematically reported, such that it is difficult to provide comparable examples for success or failure along the varied geographic and cultural regions where it occurs. Interventions to address abandonment encompass providing material aid, improving standards of care, and providing families with better information on disease and treatment (Howard, Ribeiro, & Pui, 2005; Spinetta et al., 2002). Specific examples include introducing a medication diary for children with acute lymphoblastic leukemia (ALL) in Indonesia (Sitaresmi, Mostert, Gundy, Ismail, & Veerman, 2013) and providing extensive cancer and treatment information, along with assistance with transport expenses and other family needs, in Brazil and Central American countries (Howard et al., 2004; Howard et al., 2005; Rossell, Gigengack, & Blume, 2015). However, a cancer diagnosis also causes a family to lose income during hospital attendance and incur expenses not covered by institutional subsidies (Israels et al., 2008; Mostert, Guna-wan, & Wolters, 2012; Tsimicalis, Stevens, Ungar, Mckeever, & Greenberg, 2011). Aid provided in the community might positively influence parents' decision-making and their ability to attend their child's treatment.

Collaborative strategies involving multiple local institutions or resources in LMIC have not been well developed or documented. However, community resources, specifically nonprofessional health care workers, have been used successfully in constrained settings to supplement facility-based medical services, especially for mental health care and for preventing infant and maternal mortality (Haver, Brieger, Zoungrana, Ansari, & Kagoma, 2015; Selamu, Asher, & Hanlon, 2015). Even though cancer treatment cannot be referred to local clinics, similar strategies involving resources that are not necessarily health related can provide support for completing medical treatment.

### ***The Salvadoran childhood cancer program***

In El Salvador, governmental resources do not cover the expenses of long-term care or treatment other than medicines and medical attention in national hospitals. Therefore, the support of nongovernmental organizations (NGOs) is needed to guarantee a basic level of services for chronic diseases like childhood cancer. All children younger than 12 years who are newly diagnosed with cancer (approximately 200/year) receive free treatment, regardless of their socioeconomic status (SES), at the Benjamin Bloom National Pediatric Hospital, which is supported by two nonprofit groups: the Fundación Ayúdame a Vivir (FAV) [Help Me to Live

Foundation] and the Asociación Salvadoreña de Padres y Amigos de Niños con Cáncer (ASAPAC) [Salvadoran Association of Parents and Friends of Children with Cancer].

Strategies to reduce abandonment in El Salvador have mostly targeted the psychosocial and financial needs of the families. Improved diagnostic communication procedures were based on a multidisciplinary team approach involving a nurse educator, psychologists, social workers, and a physician, leading to better informed parents and children (Rossell Curcó, 2001). Provisions for the poorest families include meals and accommodation for parents staying at the hospital with their child, money for transportation, payment for imaging and screening tests performed outside the hospital, food baskets for families returning home after a hospitalization, and payment of funeral expenses (Bonilla, Rossell, & Salaverria, 2009). The multidisciplinary team determines the kind and amount of assistance that a family receives based on the social worker's evaluation and team discussions in special cases. These interventions improved the quality of psychosocial services, and the rate of treatment abandonment decreased substantially from 22% in 1999 (Bonilla, Moreno, & Marina, 2000) to 13% over the past decade (Bonilla et al., 2009). In 2011, the introduction of the time sensitive adherence tracking procedure (TS-ATP) for patients who missed hospital appointments, provided the first reliable data on treatment absenteeism in El Salvador and helped further reduce abandonment rates to 3% in the reported years of 2011 and 2012. The main reasons for missing appointments were (1) lack of funds; (2) unexpected events, such as weather conditions or transportation problems; and (3) circumstances related to family dynamics, such as another family member being ill or the primary caregiver having conflicting responsibilities (Salaverria, Rossell, & Hernandez, 2015).

The TS-ATP was a teamwork strategy linked to the patient's scheduling system: patients who missed appointments for treatment or medical checkup were detected and contacted on the same day of the absence. If contact failed, local institutions, such as health units and municipalities were asked to locate the families, and to help them, especially if their absenteeism was related to a lack of money or transport. The process of early detection and reaction in the TS-ATP was possible due to an improved computer-based management of the steps involved in each child's hospital appointment. The appointment and the steps expected were programmed in advance in each clinical visit according to the treatment protocol, and the personnel involved in each step would carry out specific checks that allowed them to quickly detect when a child missed either an appointment or a step of the programmed plan. Close follow-up of each absent child and the result of the contact were registered in a database (see Salaverria et al., 2015 for the detailed TS-ATP strategy). The success of the intervention resulted in the expansion of the contact with local institutions to include families at high risk of abandoning treatment (e.g., for a lack of financial resources), even if they had not missed hospital appointments.

Here we report our experience soliciting voluntary support from community institutions as an additional strategy to address and prevent absenteeism and treatment abandonment, and how parents experienced and perceived this intervention. The registered information and interview data on which this report is based has come out of the continuing process of improvement and expansion of the TS-ATP strategy. By coming out from an ongoing intervention, this research resembles most closely action research (Berg & Lune, 2012), in particular due to the progressive systematization of data collection and the importance of reflexive analysis along the intervention.

## **Method**

This is a mixed-methods exploratory research in which we created a database recording patients' absences and the follow-up activities by hospital staff in regard to secure treatment continuation, and community institutions participation. Subsequently, we followed up with qualitative interviews with parents and staff members to provide insight into the tally of our database, especially in regard to the usefulness of community resources to prevent absenteeism and/or abandonment.

### ***Setting and patients***

Most families who come to the Benjamin Bloom National Pediatric Hospital are poor, as one-third of the population of this country lives in poverty (World Bank, 2015). Data from the social worker's assessment of families' SES reveals that approximately 70% of families in the program survive on a monthly income of less than US\$50 from informal, temporary jobs. Families who earn up to the minimum wage (\$250) are 16%, and only 14% reach an income higher than that. Approximately half of the children come from rural areas.

On admission, the social worker, psychologist, and nurse educator assess the family's resources and general risk factors that could hinder the child's completing treatment. Besides the social worker's socioeconomic questionnaire (inquiring location and type of household, number of family members, breadwinning activities, average expenses, etc.), the psychologist and the nurse educator individually conduct interviews and assess the family while providing information from their area of expertise, which complements medical and practical information for the functioning of the newly diagnosed families at the hospital. This interaction provides the team with a sense of the social risks and resources of the family, as well as personal and family attitudes toward the new condition they have to adapt to. Families identified as socially or economically vulnerable to the extent that treatment attendance is at risk receive special attention.

### ***Contact with local community institutions***

To help locate missing patients and prevent absences of children with significant economic or other limitations, parents were offered the option of having hospital

staff contact a local office in their community to request support. All the families accepted the offer. A psychologist or social worker contacted the local municipality offices or health units (local national clinics for primary health care within their designated area) by phone, if a child missed an appointment and could not be located promptly. The community institutions sent social or health promoters to visit the family at home, to help or encourage them to return to the hospital, and subsequently reported their findings to hospital personnel. Through follow-up phone calls or letters from the hospital, continuing help for the families was coordinated with the collaborating community institutions.

In the case of families identified as being socially or economically vulnerable (regardless of missing hospital appointments), contact with community institutions would take place through a letter sent to the parents. Personnel at these institutions were informed of the child's diagnosis, the importance of treatment, and the value of their voluntary support in enabling the child to continue treatment. The request for help was general and open to the available resources of each institution.

### ***Data collection and sources of information***

The data presented here are drawn from a database that tracks patient absences and subsequent follow-up action. This report analyzes the data collected from January 2011 to December 2013. First, the database records interactions with the community institutions, and contains entries on frequency of and reasons for children missing appointments, the number and type of community institutions contacted for help, their responses, and the type of help they provided.

Second, the database records follow-up contact with the families. For each missed appointment, members of the psychosocial team phoned the parents and asked the reason for their absence. Follow-up interviews were held at the hospital in cases where information by phone or previous contacts seemed insufficient, contradictory, or was not possible. The parents were asked the type of obstacles they had for attending treatment, main possible solutions at hand, chances for such obstacles to represent a regular problem for treatment adherence, etc.

In order to gain a better understanding of these obstacles and how follow-up might be improved, NR and CS conducted qualitative in-depth interviews with a select number of parents (17). During these interviews, parents were asked their opinions about the help received or their experience with the local institutions, which allowed us to get a better sense of the lived experience of the families assisted by these services. We include some of the stories told by the parents below.

In addition to these interviews, our analysis is guided by NR's participant observation of the multidisciplinary team activities, including staff procedures meetings and case discussions. Also, informal interviews with hospital staff were held to know their opinions and lessons learned from the handling of the inter-institutional relations and contacts, their view of the parents' involvement, and the main

difficulties encountered in the inter-institutional exchanges. In short, the qualitative follow-up was meant to provide a better understanding of the strengths and weaknesses of this intervention, and its impact on parent's perceptions of, and engagement with, the treatment.

## **Results**

### ***Resources and mobilized support***

During the 3-year period reported here, the hospital team contacted 118 community institutions to help 206 children: 110 health units or municipality offices, 7 local NGOs, and 1 church. Each territorial area (village or town) has municipal offices and health units that provide services within definite geographic limits. The institutions were contacted based on the correspondent territory to which each family belonged. Some institutions were contacted twice or more if more than one family happened to live in their area of influence. NGO's or churches were contacted if the parents reported to the hospital staff that such institutions ran relevant projects in their town.

In most cases, the community personnel showed interest and willingness to help the family, whether or not they actually followed through. No response or help was obtained in 73 cases (35%). Of those institutions that responded positively, 83 searched for absent patients, 60 transported parents to the hospital in institutional vehicles, 55 provided money for travel expenses, 7 provided food baskets, and 23 provided a one-time-only monetary aid. A total of 128 children (62%) benefited from this collaboration, resulting in an estimated expenditure of US\$27,700, or approximately US\$72 per child per year (this calculation considers only costs of transportation and travel expenses).

In the process of locating absent parents and the follow-up once they returned, 1,913 phone calls and 873 face-to-face interviews were conducted, enquiring parents about reasons for absences, and considering new more effective alternatives of help especially in cases of repetitive absences. The length of the interviews varied from 5 to more than 60 minutes, but most of them (87%) took less than half an hour.

### ***Parents' challenges and experiences with support***

Despite the help received through community institutions, attending hospital appointments involved financial and nonfinancial costs beyond transportation, food, and lodging, so the practicalities of undergoing treatment still imposed some burden. However, the immediate benefit gained from solving a financial or practical difficulty made the whole effort seem worthwhile.

Parents provided with transportation arrived at the municipality office or other meeting point early in the morning. Those who received bus fare in cash had to phone or visit the community office to learn when they could obtain the money.



The families incorporated these procedures into their routines for attending treatment. The two main difficulties parents reported were irregularities in the local institutions' systems that resulted in a vehicle or money being unavailable, and lack or irregular access to the appropriate contact person. Parents often had to call or visit the office repeatedly to inquire about promised help, which depleted their phone credit or funds for public transport. On other occasions, parents were uncertain if local institutional help would be available until the last minute. In all cases, parents needed to coordinate home logistics in advance, for example, arranging food, household chores, or more complex matters, so that family activities could continue while the caregiver was at the hospital. In some cases, the need to coordinate logistics with the community institution in addition to the hospital required parents to modify their plans. For example, one mother explained that if the institutional vehicle was late arriving at the meeting point, she would set off for the hospital by bus to avoid being late and thereby delaying the treatment process until later that day. If that happened, she might stay in the hospital's temporary accommodation overnight rather than risk returning to her home in an unsafe area in the late afternoon or evening, but this precaution interfered with her domestic responsibilities, and her family worried if she could not notify them of her changed schedule.

Another mother stayed overnight with fellow church members who lived closer to the center of the municipality, so that she could leave for the hospital early in the morning without having to walk a long way through the forest in the dark. However, this required her to make arrangements at home 2 days before her child's appointment.

One father would visit the municipality every week on the day before his child's appointment to receive money for the bus. Occasionally, funds were unavailable and he had to borrow money from neighbors. Asking neighbors for small and frequent loans is common in El Salvador, but when parents counted on a secure source of financial assistance from a local institution, this unanticipated lack of funds added last-minute obstacles to attending their child's appointment. Some parents had no money other than that received from the local community institution, whereas others had small savings.

One father rejected an offer of municipal transportation because the vehicle was only available when other errands were run in the capital, requiring the father to adapt his trip to the driver's schedule and priorities. The father considered that he could not risk his child's scheduled treatment, despite greatly needing this support.

Overall, parents found the help from their local communities useful and, for some, even essential for attending their child's treatment. Parents were generally thankful, and most dismissed inconveniences as unimportant, assuming they were unavoidable. One mother said: "*Probably I wouldn't come [to the hospital] without this help. When they get delayed [providing her with bus fare], I bake and sell some bread and I travel with that money. I can't work every day because I have to be here [at the hospital] so often.*"

The support was sometimes intermittent. George, a teenager whose leg was amputated, travels to the hospital approximately 12 times a month by taxi, which costs \$24, a sum his mother cannot afford. The day before each appointment, his mother calls the municipality for assistance, but institutional transport is frequently unavailable: *"...at the end, calling is useless because most of the times they can't take me to the hospital. Sometimes, I have to wait long before they come to pick me up, but I do not complain because they are not obligated to do this; I call them because I have need of their help."*

In contrast, Francis' mother is highly satisfied with the help offered by her municipality. She lives in a village 2 hours from the hospital. Francis is an 11-year-old with a brain tumor that impairs his walking, and he sometimes uses a wheelchair. *"Only twice they [the municipality] could not take us to the hospital. Once I called the driver the day before [the appointment] and he confirmed that he would pick us up at home at 4:00 am, as usual. Right after he called back and said that the car had no gasoline left, I managed to tell some friends the problem and I collected \$20.00 from them. With that we traveled by bus. The social worker at the hospital gave me \$5.00 to help me to return home. I haven't missed one single appointment in the whole year."*

### **The psychosocial team's experience**

The repeated exchanges between hospital personnel and local community institutions enhanced collaboration, provided local personnel with information about childhood cancer and the importance of treatment adherence, and increased awareness of the parties involved about how the community institutions and the oncology team provided their respective services. According to the perception of the hospital staff, the personal interest and professional skills of particular community functionaries made the help more efficient for families, and likewise, uninterested individuals were more difficult to work with, and their provision of help was less reliable.

Either the social worker, nurse, or psychologist would take up the role of contacting third-party institutions, and usually they would follow a case from beginning to end to avoid unnecessary reupdating. Because the appointment frequency varies according to the child's diagnosis, it was difficult for the hospital team to have up-to-date information about the continuity of institutional help and to track each child on a frequent basis. Case monitoring was done mainly when parents reported issues requiring institutional follow-up, particularly when the parents were receiving support on a more or less regular basis but irregularities were becoming too frequent. The hospital staff would call and inquire about the situation, and try to establish whether something could be done on the part of the hospital, like, in some cases, reconsidering a treatment schedule to coincide with the community institution availability of transport. The inter-institutional follow-up was difficult and time-consuming because usually it would take several calls and

messages to locate the responsible functionary in the offices, or the functionaries would have limited decision maneuver and it would require a balance of gentle but constant pressure to get things solved.

## Discussion

This article describes a strategy to avoid or diminish nonadherence to treatment appointments for children with cancer by soliciting the participation of community institutions. Implementing the TS-ATP and community institution support reduced the incidence of treatment abandonment from 13% to 3%. (Salaverria et al., 2015) Although the precise contribution of using community resources to lowering the rate of abandonment is unknown, the initiative provided resources for those families with the most need without increasing the economic stress on the cancer support organizations. Parents found this support essential for their child's treatment but also encountered challenges in making the procedure work amid irregularities.

This initiative originated in the hospital team's experience and understanding of the situation of the families and stimulated efforts to mobilize community institutional support. For the hospital staff, the benefits outweighed the extra time spent tracking and monitoring children outside the hospital. As a strategy to address absences and abandonment, this initiative provided families with valuable material resources but the element of unreliability further complicated the already difficult lives of some parents. How a family perceives the costs and benefits of relying on community institutions' help may affect the risk of nonadherence and abandonment.

### ***Financial scarcity as key constraint for families and institutions***

Initiatives in several countries show that improving families' material conditions helps reduce abandonment (Howard et al., 2004). As in other countries, (Suarez, Piña, & Nichols–Vinueza, 2015) financial issues were the main reason for nonadherence to appointments in our group of parents. The financial burden of a cancer diagnosis includes not only the cost of specialized medicines and frequent hospital visits but also the depletion of resources for family sustenance and reduced income through missed work (Israels et al., 2008; Mostert et al., 2012; Tsimicalis et al., 2011). The cost of transportation to the hospital substantially affects family finances, particularly for those living far away (Fluchel, Kirchhoff, & Bodson, 2014; Wakefield et al., 2014). Therefore, transportation assistance from community institutions addresses the most frequent cause of nonadherence to appointments for cancer treatment.

Hospitals and foundations in LMIC have scarce resources to meet even basic standards of care by providing additional medicine and medical personnel, and the extra help that families need to complete treatment represents a significant burden for local cancer support programs. In such circumstances, a resource-poor

program that must cover families' needs beyond their children's treatment requires creativity and commitment.

### ***Individual experiences illustrate complexity of financial limitations***

Although the parents recognized their local community's help as essential, a few found the uncertainty of the support annoying and disruptive. Therefore, what the hospital team saw as a general solution for families at risk for nonadherence was seen by some parents as a new source of difficulty requiring them to deal with yet another institution, as what started as an arrangement between institutional representatives had to be subsequently handled by the parents.

Parents with financial alternatives or more resources were less willing to accommodate the conditions of community institutional support to receive help. This shows that people value their autonomy in decisions about the use of their time and money, even when there is little room for maneuver. Parental decisions that appear wrong, impractical, or lacking in priority setting might actually signify a perceived lack of reliability of resources or weak governance at community institutional levels. Most parents could navigate a certain level of uncertainty when facing the precarious nature of community institutional support. However, the hospital team must continue to monitor the relationship between parents and community institutions and evaluate whether the support is successful or if failures could become a new reason or justification for nonadherence or abandonment.

### ***Value of team effort and community resources***

Our previous findings regarding this intervention do not suggest that nonadherence per se leads to abandonment (Salaverria et al., 2015). Rather, the pathway to abandonment may involve other routes, and nonadherence does not usually signify abandonment unless the motive is solely material scarcity. In cases of severe financial difficulties, starting interventions after the first missed appointment will likely help the parents to not abandon treatment of their child, even if they continue to miss appointments sporadically. Most parents with a history of many absences will apparently continue coming as best they can; they do not doubt the efficacy of the treatment, nor do they intend to ultimately abandon it. This represents a primary incentive for providing economic relief to families as a first step toward tackling abandonment. In more complex situations, where financial issues are only part of the motivation for abandonment, an individualized approach by the psychosocial team and a good relationship between the health team and the parent may provide a better basis for reducing the number of absences and the chance of abandonment. Cultural sensitivity and appropriate interpretation of, and respect for, families' needs are essential for the best healthcare team–family relationship. Cultural considerations and spiritual beliefs in pediatric cancer treatment are studied increasingly in the face of multicultural scenarios for health care provision (Wiener, McConnell, Latella, & Ludi, 2013). It is equally relevant to consider how social class, schooling,

and the urban-rural divide play a role in shaping doctor-parents relationships. Taking into account the socio-cultural circumstances and resources of the families is essential, particularly in settings where socioeconomic aspects play a crucial role in decision-making processes in health and other aspects of family life.

A steady, coordinated effort was a key element in the successful outcomes of inter-institutional collaborations reported here. Also essential was the experiential knowledge of the psychosocial team, facilitating balanced interpretation of parent interviews, coordination of multiple perspectives to better understand needs and allocate help, coordination with community institutions, and follow-up and registration of each case. Through their participation, local institutions became aware of the families' situation and the optimistic outcomes for childhood cancer treatment in the country.

Such a collaborative effort may be applied to reduce treatment abandonment in other countries; however, fundamental conditions must be present, such as access to phone lines to reach parents and institutions. In countries with less efficient road and communication networks or which lack suitably interconnected levels of attention within the health system, establishing inter-institutional collaborations can be challenging.

Our intervention was circumscribed to material resources provided to families by local community institutions. However, these institutions, together with other local resources, might create collective support, not limited to financial aid, for families struggling with a child with cancer. If promoted or encouraged, this more comprehensive support will likely counteract feelings of hopelessness and reduce the incidence of abandonment. Implementing and evaluating such collaboration is challenging but could provide important lessons for managing childhood cancer and other health issues in constrained settings.

Standardized screening facilitates comprehensive attention for psychosocial needs of families of children with cancer (Kazak, Barakat, & Hwang, 2011). However, screening tools do not have indiscriminate use, and applicability and results, have serious validation issues beyond the population in which such instruments have been developed. Although such instruments are not part of the clinical practice in El Salvadoran cancer program, this report shows the relevant impact that systematization of data collection and the analysis of clinical interventions can have on the improvement of services for the families.

Further improvements of this intervention include optimizing the psychosocial data collection, and its use for quantitative and qualitative analysis of the results. The Salvadoran program is integrating information on psychosocial data and inter-institutional collaborations for each patient into a computerized system. This will facilitate the follow-up and analysis of individual cases, keeping personalized clinical interventions, and expanding possibilities for research. This system will serve as a tool tailored to the psychosocial needs and circumstances of the El Salvadoran program.

Feedback from the community institutions was not collected. Implementing strategies to hear feedback about the collaborative relationship might help to improve ongoing and future interventions and could initiate a path toward formalizing relationships between the institutions involved. Moreover, in order to enhance its impact and proper documentation, this experience opens up the possibility of following up with an intervention research approach, in particular through Community-Based Participatory Research, which, by drawing on the active participation and perspective of the parents and the institutional functionaries, could expand our comprehension of the elements that are important to consider when trying to understand and combat absenteeism.

### **Limitations**

The intervention was conducted in the sole childhood cancer treatment center in a small Central American country, precluding generalizations about the results. However, from the literature regarding treatment adherence and abandonment in LMIC, we have identified commonalities in family challenges, and our report will, therefore, likely be helpful to others. Another limitation is the participation of multiple hospital professionals who gathered information without a standardized collection tool. Therefore, these should be considered pilot data; future data collection will be more comprehensive and systematic.

### **Conclusion**

By using a committed team and basic resources for communication, a hospital can reach a family's community and help parents continue their child's treatment by assembling the necessary resources. The participation of community institutions brought financial relief to both the families and the cancer program and allowed the children to continue treatment.

The parents' experiences as resource beneficiaries at the center of inter-institutional efforts must be considered when strategizing how to streamline the procedure. Where institutional organization is frail, individual contact and a more personalized approach can foster goodwill as a starting point for allocating limited resources efficiently. Creating stronger links among local institutions, the hospital, and foundations, and optimizing the terms of collaboration should be future aims of this intervention with multicenter participation.

Further progress can be achieved by developing guidelines for this type of inter-institutional collaboration, in order to reduce the uncertainty of support, maximize resource provision, and minimize the burden on the families. General guidelines could include a categorization of the types of assistance or contributions expected from the participating institutions, and, at an operational level, for those who are in direct contact with the families in their communities, the identification of events that should be followed up by case updates among institutions.

Our experience shows that a process that integrates a robust appointment tracking system, an immediate response to absences, and resources from community institutions to enable treatment adherence can be implemented at relatively low cost to reduce treatment abandonment in LMIC. The possibilities for advocating a formal systematic collaboration involving diverse institutions of private and government sectors should be considered.

### Conflict of interest

The authors have no conflict to declare.

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