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Psychosocial risk in pediatric cancer patients and the perceived usefulness of available care resources by their caregivers

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ABSTRACT

Introduction. Pediatric cancer exposes families to numerous chronic stressors, which require resources that are often lacking in vulnerable settings.

Objectives. To assess the psychosocial risk among pediatric cancer patients and to explore caregivers' perceptions of the usefulness of the psychosocial support services offered by hospitals.

Population and methods. This was an observational, prospective, descriptive, cross-sectional study. The study included caregivers of patients with a recent cancer diagnosis from five Argentine hospitals. Participants were administered the Psychosocial Assessment Tool (PAT) questionnaire and a hospital psychosocial intervention inventory designed for this study.

Results. The sample consisted of 103 subjects. Public and private hospitals obtained similar risk scores. Average risk: moderate. The sample was distributed as follows: low risk (43%), moderate risk (41%), and high risk (16%). The areas of highest risk were family structure and resources, stress response, and parental problems. All institutional measures aimed at strengthening financial resources were reported as highly helpful. The choice of other types of interventions varied, with particular emphasis on the usefulness of those directed at patients and at strengthening social support. Interventions aimed at treating caregiver psychopathology were considered less useful, despite this type of problem being one of the most prevalent among parents at high and moderate psychosocial risk.

Conclusion. This study assessed the psychosocial risk among pediatric cancer patients in Argentina, identified the psychosocial interventions offered by hospitals, and examined caregivers' perceptions of the usefulness of these interventions during the first month following diagnosis.

Keywords: *neoplasms; pediatrics; hospitals; mental health services; social services.*

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INTRODUCTION

More than two-thirds of pediatric cancer cases worldwide occur in low- and middle-income countries.[1] In Argentina, approximately 1360 new cases are diagnosed each year.[2]

Pediatric cancer exposes families to numerous chronic stressors, which require resources that are often lacking in vulnerable settings. Studies report that psychosocial stress at diagnosis is associated with higher levels of subsequent stress and greater use of healthcare resources.[3,4] High levels of stress and psychopathology in caregivers are associated with poor coping and negative health outcomes for children with chronic illness.[5,6] Furthermore, when parents cope effectively, children's personal growth increases.[7,8]

Poverty is one of the main barriers to healthcare access among the Latino population and a significant source of stress for caregivers.[9] Recent studies identify it as a factor influencing the course of pediatric cancer. Poverty and inadequate housing conditions have recently been linked to poor treatment adherence among pediatric cancer patients.[10] Socioeconomic risk factors such as economic instability, unemployment, and lack of health insurance, along with the heavy financial burden that transportation, communication, housing, and food costs place on these families, are a constant source of stress for caregivers of children with cancer.[11,12] Caregivers with higher incomes reported greater satisfaction with the resources provided by the hospital treating their children, while those with lower incomes reported lower satisfaction, despite receiving similar services.[13]

Psychosocial interventions in hospitals in Argentina are carried out without a systematic understanding of the psychosocial risks of the local population and without being grounded in the recommendations outlined in international consensus documents. Psychosocial interventions may thus prove inadequate in addressing the needs of the population to which they are applied. Hence, the importance of understanding the psychosocial risk of the local pediatric oncology population and identifying the hospital support resources preferred by caregivers.

We hope that this study will promote the development of hospital-based psychosocial intervention resources capable of mitigating the consequences of such high demands.

OBJECTIVES

- To characterize the psychosocial risk among children with cancer in Argentina.
- To explore the degree of usefulness that families assign to psychosocial care resources.

POPULATION AND METHODS

Study type

Prospective, descriptive, cross-sectional observational study.

Population

Parents/caregivers of pediatric cancer patients treated at four high-complexity public pediatric hospitals—which serve as referral centers within the National Pediatric Oncology Health Program—located in the Autonomous City of Buenos Aires (CABA, by its Spanish acronym), Santa Fe, Mendoza, and Santiago del Estero, as well as a private general hospital that primarily serves patients with private health insurance. The latter is also part of the country's pediatric oncology care network.

Inclusion criteria

Caregiver of patients aged 0 to 17 years with cancer undergoing active treatment up to 33 days after diagnosis.

Exclusion criteria

Caregiver for critically ill patients and/or those requiring intensive care, patients receiving exclusively palliative care, and patients requiring exclusively surgical treatment.

Sampling

Purposive. Parents and caregivers of inpatients and outpatients were invited to participate consecutively.

The relevant ethics and research committees approved the protocol. Participants signed informed consent forms to confirm their voluntary participation. Data were collected between December 2023 and August 2024.

Instruments

PAT (Psychosocial Assessment Tool) questionnaire[14] for assessing psychosocial risk across seven areas: 1) family structure and resources, 2) social support, 3) the child's problems, 4) sibling issues, 5) parental issues, 6) reaction to stress (caused by the diagnosis), and 7) family beliefs (regarding the illness). It identifies three general risk levels: low, moderate, and high, and quantifies the risk in each area. Translated into Spanish for the Argentine population. The Spanish

version proved to be a reliable and valid measure of family psychosocial risk.[15]

Inventory of psychosocial resources: an instrument developed for the study that identifies 21 psychosocial care resources, as reported by social workers and psychologists from the Sociedad Argentina de Hemato-Oncología Pediátrica (SAHOP, by its Spanish acronym). Caregivers assign a level of usefulness to each resource. The interventions were organized around the seven risk areas of the PAT: financial resources; social support; the patient's, siblings', and parents' mental health; the impact of the diagnosis; and partnership with the healthcare team. An open-ended question regarding unmet needs and suggestions was included.

The researchers administered the assessments.

DATA PROCESSING

The populations of public hospitals and the private hospital had similar sociodemographic and psychosocial risk characteristics, so the results are presented together.

The sample was described using frequency analysis, as was the utility assigned to the intervention resources. In both cases, the results were expressed as percentages.

RESULTS

The sample consisted of 103 subjects from the Hospital de Pediatría Dr. Prof. J. P. Garrahan (N = 59), Hospital Dr. H. Notti (N = 12), Hospital Militar Central (N = 12), Provincial de Salud Infantil Eva Perón (N = 10), and the Hospital de Niños Dr. Orlando Alassia (N = 10). The mean age of the patients was 7.64 years (SD 4.86), with a population ranging from 0 to 17 years; 58% were male, and 42% were female. The majority (95%) were Argentine. The distribution by diagnosis was 68% leukemias and lymphomas; 20% solid tumors, and 12% central nervous system tumors. Fifty-nine percent of the patients had public health coverage; 38% had employer-sponsored health insurance; and only 3% had private health insurance (*Table 1*).

Eighty-nine percent of the caregivers were mothers, almost all of whom were over 21; 66% lived with a partner, and 34% were single parents; 44% of these caregivers had not completed compulsory education; 75% reported few or no financial problems, but 25% reported many problems or an inability to meet basic needs (*Table 2*).

The distribution of psychosocial risk was 43% low, 41% moderate, and 16% high; the moderate category (X = 1.25) represented the average risk.

The areas associated with the highest

Table 1. Sample description (n = 103)

		N (%)
Medical center	Hospital Garrahan	59 (56)
	Hospital Notti	12 (12)
	Hospital Militar Central	12 (12)
	CePSI Eva Perón	10 (10)
	Hospital Alassia	10 (10)
Patient provenance	Buenos Aires and CABA	38 (36)
	Mendoza	12 (12)
	Santiago del Estero	11 (11)
	Santa Fe	11 (11)
	Other provinces	26 (25)
	Foreign patients	5 (5)
Diagnosis	Leukemias and lymphomas	70 (68)
	Solid tumors	20 (20)
	CNS tumors	13 (12)
Patient age (years)		X = 7.64 (0-17)
Sex	Male	60 (58)
	Female	43 (42)
Health insurance	Public health	61 (59)
	Health insurance	39 (38)
	Private health insurance	3 (3)

CABA: Autonomous City of Buenos Aires (by its Spanish acronym); CNS: central nervous system.

psychosocial risk were family structure and resources, stress response, and parental problems. The area associated with the lowest risk was social support (*Figure 1*).

The factors that contributed to risk in the area of family structure and resources were having public health insurance, lacking personal transportation, and the caregiver's low level of education.

The stress response in this sample revealed that 53% of parents experienced cognitive, emotional, and/or somatic symptoms consistent with acute stress, particularly "feeling nervous, anxious, or having a rapid heartbeat when recalling their child's illness." Twenty-four percent of caregivers experienced these symptoms most of the time.

Among the parents' problems, the following were reported: "concern or anxiety within the family", "grieving the loss of a loved one", "stressful family issues", and "having experienced violence or abuse." Between 15% and 20% of caregivers reported suicide attempts, alcohol and drug problems, relationship issues, and legal disputes over child custody.

Social support emerged as a source of strength, even in single-parent families, thanks to the financial, caregiving, and emotional support provided by relatives.

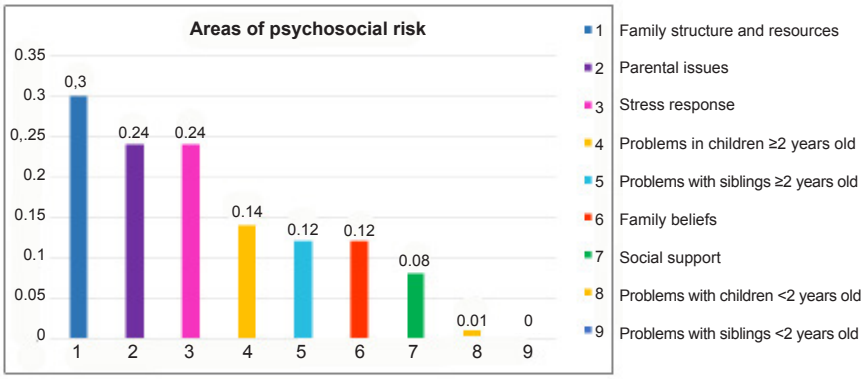
Nearly all respondents had positive expectations about healthcare workers' performance and their own ability to navigate and overcome the situation.

Among hospital-based intervention resources, caregivers preferred those aimed at improving financial resources, strengthening social support,

Table 2. Sample description. Characteristics of the primary caregiver (n = 103)

		N (%)
Primary caregiver	Mother	92 (89)
	Father	9 (9)
	Other	2 (2)
Age	Under 21 years old	1 (1)
	21 years old or older	02 (99)
Marital status	Single, separated, widowed	35 (34)
	Married, cohabiting	68 (66)
Educational level	Primary education	16 (16)
	Completed primary education	4 (4)
	Incomplete secondary education	25 (24)
	Completed secondary education	31 (30)
	Tertiary/university education	27 (26)
Financial difficulties	Few/none	75 /77)
	Many/unable to meet basic needs	25 (26)

Figure 1. Psychosocial risk level by area



and optimizing patients' emotional well-being (*Figure 2*).

Interventions targeting issues such as violence, substance use, and caregiver psychopathology were met with very low acceptance, even among those who reported experiencing these situations (*Figure 3*).

The resource inventory revealed that 84% of caregivers had no conflicts with the healthcare team and that 22% found it difficult to follow all medical instructions.

Caregivers did not suggest other supportive interventions.

DISCUSSION

This is the first study conducted in Argentina to assess psychosocial risk in pediatric cancer patients. The level of risk observed in this sample

Figure 2. Care resources chosen by more than 70% of the caregivers

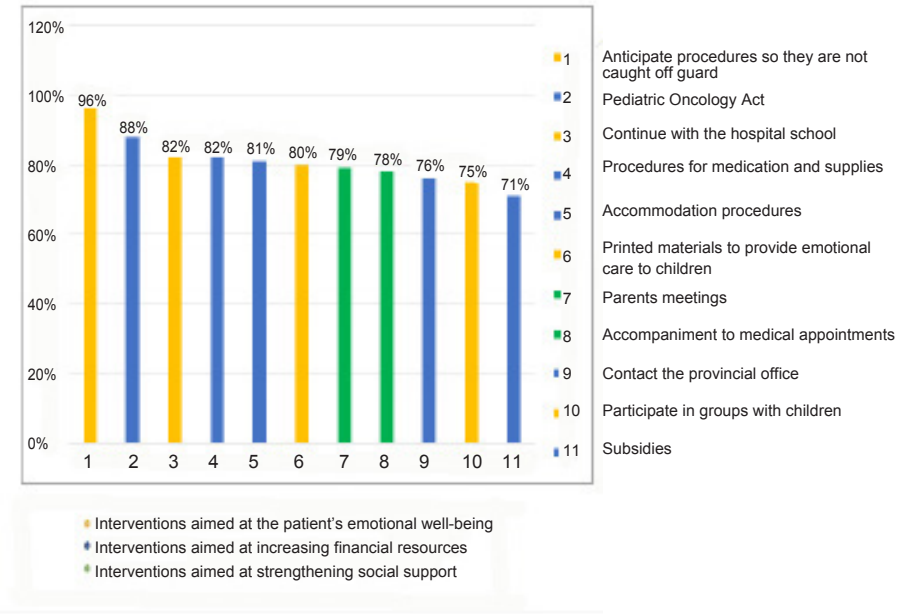
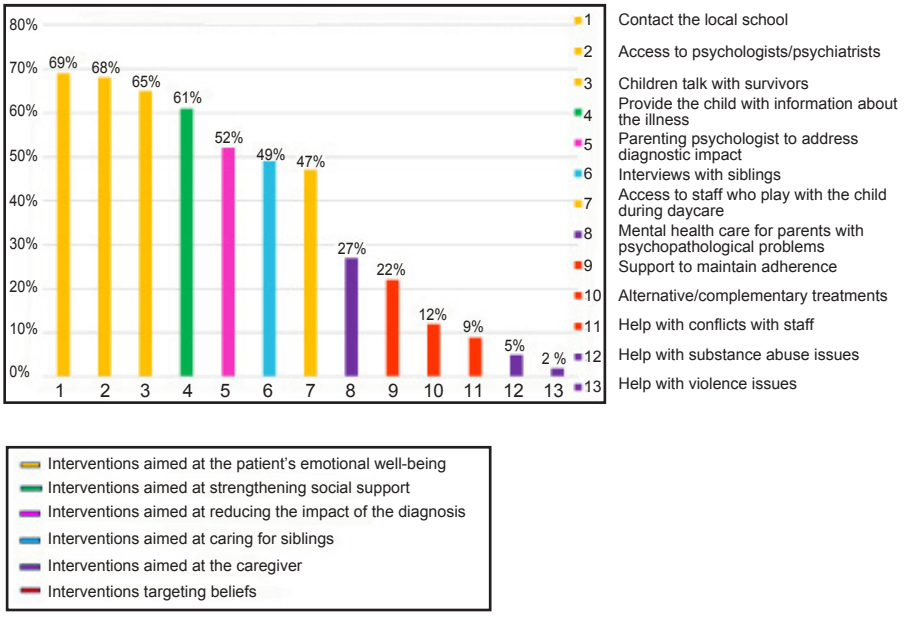


Figure 3. Care resources chosen by less than 70% of the primary caregivers



was lower than that of the Latino population included in the normative samples from Philadelphia (United States) and Melbourne (Australia).[14] The higher risk recorded in that sample could be explained by cultural differences between Hispanic and U.S. populations, related to health beliefs and behaviors, dietary habits, communication styles, and language—factors previously identified in the literature as barriers to access and healthcare.[9]

Furthermore, some responses appear to reflect the caregiver's subjective perception rather than the objective conditions they refer to. This perception may differ between migrant and Hispanic populations in the United States and the non-migrant population in Argentina. In this sample, for example, most caregivers reported few financial difficulties, even though other indicators suggest a less favorable situation.

The characterization of psychosocial risk by domain in this sample shows similarities to findings from other studies of the Latino population, with family structure and resources as the domain of highest risk and social support as the domain of greatest strength. Family beliefs were also identified as a low-risk domain.

Social support and the central role of family members as providers of assistance have already been identified as characteristics of both migrant[9] and non-migrant[16] Latino groups.

The caregivers' beliefs about their situation proved to be a source of strength, as they demonstrated high confidence in both the healthcare team and their own coping resources.

Regarding the stress response following diagnosis, consensus guidelines in pediatric oncology recommend strengthening psychological support during the early stages of the disease, as this is a particularly emotionally demanding time.[17] Psychosocial interventions during the first six months of pediatric cancer treatment have been shown to have a greater impact on family stress levels than the patient's medical history.[18]

It was expected that caregivers would prioritize interventions targeting the most pressing risk factors, but this pattern was not observed. Interventions aimed at strengthening patients' social support and emotional health were highly accepted, even though caregivers reported ample support, and the children showed very low risk. In contrast, interventions aimed at the emotional care of parents were dismissed despite the high prevalence of parental psychopathology.

The high levels of parenting difficulties observed in this sample contributed to an increased psychosocial risk. This finding is consistent with the literature, which indicates that populations with socioeconomic vulnerability and low social capital have higher rates of psychopathology.[19]

These challenges highlight the need for specific psychosocial support for adult caregivers. The low uptake of such interventions is likely linked to the need to prioritize protecting children facing a real threat to their lives, leaving little room to focus on the caregivers' own well-being. In this regard, any intervention aimed at caregivers should explicitly emphasize the protective effect that the adult's care has on the child's well-being.

Like any discipline in the healthcare field, psychosocial care should be standardized and based on empirical evidence of its effectiveness.[20] The available consensus guidelines on psychosocial care—from the International Society of Pediatric Oncology (SIOP)[17] and the Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC)—enjoy a high level of support, even though the available evidence regarding their effectiveness is still limited.[21]

A previous study showed that some of these recommendations are systematically implemented in Argentina: access to psychosocial services, information management, schooling, and care for healthy siblings.[22] Other interventions, such as neuropsychological monitoring and follow-up care for survivors and bereaved family members, are provided upon request. There is also variability in the services offered across care centers. These characteristics of psychosocial care in pediatric oncology are not unique to our country. The heterogeneity of services and their lack of a foundation in systematic studies is also reported in developed countries. A U.S. study reports that only 9% of institutions assessed psychosocial risk using objective instruments, and less than 11% implemented evidence-based treatments.[18]

The findings of this study, together with current international recommendations, could serve as a starting point for designing nationally standardized psychosocial intervention programs to promote greater equity in health care. In this regard, a key finding of this study is the distribution of total psychosocial risk, which shows that more than 80% of the sample has low or moderate levels of risk. This indicates that, in most cases, needs can be addressed through general preventive interventions, group activities, psychoeducational materials, and temporary

targeted strategies addressing specific risk factors. Such interventions—short-term and large-scale—are particularly relevant in institutions with high care demand and a high patient-to-staff ratio. The study has some limitations that restrict the generalizability of the results. First, participants were in their first month of treatment, and their assessment of the support offered may have been influenced by limited awareness of the problems they might face. Future studies should investigate whether the choice of resources varies with illness duration, for example, by administering the instrument at different stages of the disease course. Second, the sample size, equivalent to less than 10% of annual diagnoses in the country, prevents the generalization of the results. Finally, purposive sampling introduces potential selection bias that could affect the sample's representativeness.

CONCLUSION

This study made it possible to characterize the psychosocial risk profile of the local pediatric oncology population, identify priority areas of vulnerability and strength, and generate evidence relevant for the design of hospital-based psychosocial intervention strategies tailored to the actual needs of families. ■

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