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An ethnographic exploration of the delivery of psychosocial care to children with cancer in Argentina

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ABSTRACT

Purpose: The integration of psychosocial care in the routine care of cancer patients has been set as an international standard, but there are healthcare contexts where these services are lacking as psychosocial care providers are not incorporated in multidisciplinary teams and screening for psychological distress is not carried out routinely or systematically.

Method: In this article, we discuss the findings from an ethnographic study that focused on exploring the working experiences of psychosocial care providers from one children's hospital in Buenos Aires, Argentina. The study is based on 10 in-depth interviews with hospital staff members and participant observation in selected hospital areas. The transcripts from the interviews and fieldnotes from the observations were analyzed using thematic analysis.

Results: We found that psychosocial care providers encounter difficulties while attempting to deliver services to children and their families, produced mainly by their lack of collaboration with other professional groups, insufficient human resources, and a growing patient population. As a result of this situation, psychosocial care providers often prioritize some patients over others, leaving a considerable number of patients and family members without psychosocial support.

Conclusions: The study highlighted the barriers psychosocial care providers encounter while attempting to deliver services to children and their families. Further work needs to be carried out to fully integrate psychosocial care in national health policies and ensure this type of support is available for all patients and their families.

Keywords: psychosocial care, cancer, children, ethnography, Argentina

The integration of psychosocial care in the routine care of cancer patients has received a great deal of attention at an international level. Countries such as the US, UK, Canada, and Australia have led the way in the establishment of standards of psychosocial care and the development of guidelines to guarantee this aspect of the patient’s care becomes a core component of health service delivery (Jacobsen and Wagner, 2012). However, previous research has indicated that much work still needs to be done as there are still instances where psychosocial care providers are not incorporated in multidisciplinary teams, screening and assessment of psychological distress is not carried out routinely or systematically, and many psychosocial interventions are directed at patients, without including parents, partners or other close family members (Mehnert and Koch, 2005; Magrath et al., 2013).

As a consequence, many cancer patients are at an increased risk of psychological morbidities after diagnosis (Al-Azri et al., 2009). They might have to abandon treatment because they are not able to afford its costs or the costs of travel to the treatment center (Arrossi et al., 2007; Howard et al., 2007; Ribeiro and Pui, 2005). Families lack psychological counseling to cope with the patient’s treatment, and in case of the patient’s death, with support during bereavement (Holland et al., 2010). This is the case of Argentina, where psychosocial care is not delivered routinely to patients and is seldom offered after the treatment has ended. In this article, we present the experiences of psychosocial care providers in one public hospital in Buenos Aires, focusing primarily on their perceptions of the care they provide and the barriers they encounter on a daily basis.

In 2008, the Institute of Medicine (IoM) published *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* and indicated that “psychosocial care must be integrated in quality cancer care". The IoM proposed processes and goals of psychosocial care arguing that the needs of patients should be identified early in their treatment trajectory, patients should be linked to needed services during and after treatment, and family members should be screened for their psychosocial needs and provided with support (IoM, 2008).

Since the publication of this report, different associations, networks, societies, and professional groups have developed standards for the psychosocial care of patients with cancer and their families (Clark et al., 2012; Holland et al., 2010; Surbonne et al., 2010; Wiener et al., 2015). These have been listed in Table 1. The implementation of these standards into changes in practice is at different stages of development, but there seem to be emergent findings indicating that they are producing a positive effect in the psychosocial care delivered to patients and their families (see Jacobsen and Wagner, 2012 for an overview).

Table 1. Standards on psychosocial care for cancer patients and their families

Association	**Country**	**Focus**	**Reference**
Institute of Medicine (IoM)	USA	Sets processes and aims for psychosocial care	IoM, 2008
American Society of Clinical Oncology	USA	Assessment of psychosocial needs during administration of chemotherapy	ASCO, 2009
National Comprehensive Cancer Network (NCCN)	USA	Distress management	NCCN, 2010
Canadian Association of Psychosocial Oncology	Canada	Delivery of psychosocial services	CAPO, 2010
American College of Surgeons	USA	Screening of psychosocial needs and development of intervention programs.	CoC, 2011
Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC)	International	Integration of psychosocial care in all stages of the pathway	Wiener et al., 2015

Recently, a group of pediatric oncology psychosocial professionals developed a set of standards directed at children with cancer and their families through the Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC). In essence, these standards promote the integration of psychosocial care in all stages of the child's treatment pathway, from diagnosis to survivorship (Wiener et al., 2015). They establish the need for the routine and ongoing screening of the psychosocial needs of patients and their family members (placing an emphasis on parents and siblings) and the integration of professionals in charge of psychosocial care in multidisciplinary teams (MDTs) and processes affecting decisions on the child's care (Wiener et al., 2015). The main aim of these standards is to guarantee "universal access to psychosocial support and intervention for patients and family members" (Wiener et al., 2015:S424).

In this article, we examine the delivery of psychosocial care in Argentina by describing the daily working experiences of psychosocial care providers from one public children's hospital in Buenos Aires. The use of ethnographic research methods allowed us to capture the different ways in which psychosocial care providers visualize the care they provide to patients, the interactions they have with other professional groups, the barriers they encounter while trying to provide high quality care in overburdened and understaffed medical facilities, and the strategies they use to overcome them.

Cancer treatment for children in Argentina

Cancer is the most common cause of death from a disease in children from 5 to 15 years (Abriata and Moreno, 2010) and the second most common cause in those aged from 1 to 4 years (Moreno et al., 2009). The incidence rate is similar to that in some

European countries and the US (125 cases per 1,000,000 children below the age of 15) (ROHA 2015), however the survival rate is much lower (61% at five years after diagnosis) (Abriata and Moreno, 2010; ROHA 2015). Recent studies have indicated that there is a link between prognosis and place of residence, where children in Buenos Aires obtain better clinical outcomes than those located in the most economically deprived provinces of the country (located in the north-west and north-east) (Moreno et al., 2013). Potential explanations for this variability in outcomes are: the unequal distribution of specialized centers for cancer treatment, lack of training of primary care professionals on the identification of early symptoms of cancer and lack of diagnostic equipment (thus leading to longer symptom interval) (Casak et al., 1997; Chantada et al., 1999; INC, 2015).

In the case of specialized care for pediatric oncology treatment, Argentina uses a centralized model of care, where treatment is available mainly in five hospitals located in Buenos Aires (Brage et. al., 2013). There have been recent attempts to decentralize pediatric oncology treatment by building new medical facilities in other provinces, promoting the specialized training of healthcare professionals, and implementing shared care networks across regions to prevent referrals to Buenos Aires (Olaviaga and Maceira, 2007). In spite of these efforts, most children with cancer (approximately 40%) receive treatment in Buenos Aires, in the public sector (Brage et al.,2013). This centralized distribution of medical services leads to evident inequalities in the access to specialized personnel and treatment, and it forces more than 40% of all children diagnosed with cancer to leave their place of origin and relocate to a new city during some part or all of their treatment (Brage et al., 2013; Moreno et al., 2009; Scopinaro and Casak, 2002; Toziano et al., 2004). These well-established flows of patients and their families pose challenges for healthcare professionals in terms of follow-up care and psychosocial support (Olaviaga and Maceira, 2007).

Psychosocial cancer care for children in Argentina

In general, most hospitals in the country have mental health and social care services capable of providing psychosocial care to children with cancer and their families. However, very few hospitals have mental health professionals and social workers who work exclusively with oncology services. In most cases, these professionals are spread over the entire hospital, providing services for patients with a wide range of needs. This situation has an impact on the quality of care professionals are able to provide as well as their working conditions. Previous research with healthcare professionals in Argentine hospitals has already pointed to cases of stress and burnout produced by institutional factors (funding, lack of organization, etc.) (Dahlin et al., 2013; Doval, 2007; Luxardo et al., 2014; Waldman et al., 2009). We are not aware of any studies carried out with psychosocial care providers in this context.

The centralization of services mentioned above also applies to psychosocial services, leaving most children and their families without appropriate support when they return to their place of origin after treatment. This lack of access to psychosocial support represents an alarming situation, as an evaluation of the follow-up care of children with cancer in Buenos Aires indicated that approximately 50% of the cancer survivors included in the study reported emotional instability (Botana et al., 2007). The authors argue in favor of the need to use multidisciplinary approaches during follow-up to ensure a better quality of life for patients and their families (Botana et al., 2007).

The national law on Mental Health establishes the right to obtain treatment in an adequate and confidential environment. This law has been translated into regional legislation in the attempt to expand the population's access to mental health services. Great advances have been made in the integration of mental health services in primary care facilities. However, inequalities exist across the country and within provinces (mainly between urban and rural areas) (Gerlero et al., 2011). The National Cancer Institute (Instituto Nacional de Cancer) has issued national guidelines for palliative care where psychosocial care is considered an integral component of supportive care for patients receiving palliative care services and their families (Jacob and Sanchez, 2014). The guidelines for pediatric palliative care indicate that, ideally, multidisciplinary teams in charge of the child's care should be made up of doctors, nurses, psychologists, and social workers (Chacon and Zuccarino, 2013). These guidelines have only been established for palliative care, additional work needs to be done to develop guidelines for psychosocial care during active treatment.

In light of this situation, several non-governmental organizations in the form of foundations, civil society associations, and charities have developed a series of programs and "parallel" services to provide psychosocial care to patients and their families (see for instance Fundación Natalí Dafne Flexer, FNDF). These organizations provide services within hospital as well as in their own facilities (FNDF, 2015). FNDF has translated the recommendations made by the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology to Spanish. These recommendations cover a wide range of aspects of the ill child's treatment and quality of life (i.e. school, support for parents and siblings, complementary and alternative therapies, survivorship, and palliative care) and highlight the importance of a multidisciplinary approach to care delivery (Spinetta et al., 2009). Regardless of the laudable efforts of these organizations, evident inequalities in access to psychosocial care for children with cancer across the country persist. This situation has clear consequences on how children and their families deal with the emotional, psychological, financial, and social impact of cancer.

Methods

The study used ethnographic methods to capture the narratives and practices of hospital staff in charge of providing psychosocial care to children with cancer and their families. The study focused on exploring the staff members' perceptions of the care they provide, the role psychosocial care plays in relation to other forms of care provided by other professional groups, and the daily practices of delivering psychosocial care in a hospital context characterized by the lack of resources and a growing patient population. Ethnographic research methods were chosen due to their capacity to capture the complexities of daily life experience and the social processes that shape health service delivery (Atkinson and Hamersley, 2002).

The lead author carried out the study in a public children's hospital in Buenos Aires, Argentina from May 2013 to November 2015. The study used in-depth interviews with families and hospital staff members and participant observation in selected hospital areas. In this article, we only present data from the interviews and observations with hospital staff members. The findings from the interviews with families have been published separately (blinded, in press) as these cover aspects of care that go beyond the delivery of psychosocial care in this specific hospital. The protocol, information sheets, consent forms, and data collection materials were reviewed and approved by the Ethics Committee of the hospital where the study took place.

Data collection

The interviews used a semi-structured and open-ended format and followed an interview topic guide (for full list of questions, see Appendix 1). The interviews lasted between 45 to 60 minutes and, whenever possible, they took place in secluded areas or private rooms to protect the privacy of the participants. The interviews were recorded using a password protected recorder and then transcribed for analysis.

Observations were carried out in areas of the hospital frequently visited by children receiving cancer treatment and the staff members who provide care such as: in-patient wards, outpatient areas, waiting areas for social services, the hospital school, and recreational areas. The researcher documented these observations in the form of unstructured fieldnotes. The fieldnotes were transcribed for analysis.

Sampling and recruitment

The staff members were sampled purposely to account for a wide range of specialties and roles. In order to be included in the study, the staff members needed to be professionals who provided psychosocial care to children and their families and had direct patient contact. Snowball sampling was used to recruit staff members and we followed the snowball tactics proposed by Noy (2008). The sampling technique began with the identification of potential participants by reviewing the hospital directories of the relevant departments (Social Services, Mental Health, Associate Direction of Patient Care, etc.). The researcher contacted the lead staff members of each service to obtain information on staff in charge of patient care. During interviews with these staff members, the researcher inquired about other people who provided psychosocial care to children. The people who were recommended by the interviewees were then approached to see if they would like to take part in the study. A total of 10 hospital staff members (5 psychologists and 5 social workers) participated in the study.

In terms of the interviews, the researcher approached staff members directly and presented them with information about the study (communicated verbally and described in a printed participant information sheet). They were given time to look at the information and decide if they would like to take part in the study. The researcher approached them again at a later date, answered any questions, and, if they decided to take part, she asked them to sign a consent form. The interviews were scheduled at a time and place chosen by the interviewee. Nobody refused to take part in the study.

The researcher informed staff that she would be carrying out observations in the areas they frequented. Study information sheets were made available to anyone who requested additional study details. The researcher also informed people frequently attending these areas that if they did not want to take part in the study, they would not be recorded in the fieldnotes. The researcher made sure to record the notes so as to avoid the potential identification of research participants (the records were anonymized and the researcher used pseudonyms).

Data analysis

The transcripts from the observations and interviews were first anonymized and then analyzed using thematic analysis. The researcher first went through the transcripts to familiarize herself with the data. She then carried out an initial round of coding to identify salient issues in the transcripts using Atlas-ti© software. This initial list of codes was discussed with the second author and refined. This final list of codes was used to develop a codebook. All transcripts were then analyzed in relation to this codebook. After the transcripts were coded, the authors discussed the codes and searched for ways to group them into larger themes. The authors also explored potential relationships between themes. The themes and representative quotes from research participants are presented in the next section. Pseudonyms are used to refer to the research participants.

Results

As we mentioned earlier, five psychologists and five social workers were included in the study. The study participants had an average of ten years' experience providing psychosocial care to children in the hospital where the study took place. All of the participants were women. The main themes that emerged from the interviews are presented in Table 2.

Table 2. Main qualitative findings

Themes	**Main issues mentioned in each theme**
The definition of psychosocial care in our research context	• Psychosocial care is divided in two main areas: 1) Psychological support for the ill child provided by the psychologists 2) Support with administrative processes provided by the social workers • Joint working occurs only in some cases
Psychosocial care as secondary to medical care	• Medical care is prioritized due to the belief that it is more urgent • MDT working is not carried out in practice • Psychosocial care providers are asked to provide services after medical professionals have identified "problems" with patients or their family members

The institutional factors framing psychosocial care	- Low number of full-time staff - High volume of patient demand - Psychosocial care providers are only available in the hospital - Effects of institutional barriers on staff and patients o Staff experience high levels of stress o Psychosocial care is only offered to some patients o Patients and families cannot receive psychosocial care in their communities after discharge

The definition of psychosocial care in our research context

The concept of psychosocial care was used to refer to the mental health of the patient and family members as well as the wide range of social factors that play a role in processes of health, disease, and care. Our interviewees mentioned two main professional groups in charge of providing psychosocial care: psychologists and social workers. Our observations indicated that there are other professionals who also assist patients with emotional and social aspects of their care such as: hospital teachers, volunteers, artists, and play specialists. These professionals, however, did not form part of the definition of psychosocial care.

The delivery of psychosocial care is institutionalized through two main services: the Mental Health Service and the Social Work Service. The main purpose of the Mental Health Service was explained as to help the child and family members "assimilate the treatment and physical effects of the disease". The main focus is on the child, their needs, and the effects of the cancer and treatment on their emotional wellbeing. The Social Work Service aims to assist families with administrative processes required to facilitate the family's ability to adhere to the treatment schedule (i.e. transport, housing, financial assistance).

Both of these services function autonomously in the sense that staff work in separate offices, use different methods to circulate around the hospital, and apply different approaches to interact with the patients and their families. This physical separation is bypassed in cases where staff from both services need to come together to discuss issues that are relevant to both professional groups. As one of the psychologists we interviewed indicated, “pathologies such as pediatric cancer require a lot of work with many people who see different aspects of the same problem. The team then needs to be interdisciplinary”. This process of coming together is referred to as an “interconsultation”; it is not used in all cases, but only in those where there are psychological and social factors that might affect the *whole* family.

Some of the cases identified as “affecting the whole family”, and, thus, requiring joint working, were cases of migrant families and those where medical professionals suspected there was a high risk of the abandonment of treatment. In the words of one of the psychologists we interviewed, “some do not refuse treatment openly, but they stop coming [to clinic]. If they don’t come, we let the people in charge of the defense of children’s rights know. This is something we share with Social Work. Sometimes they call, but, most times, we call”.

Even though the joint working dynamic was portrayed as requiring the same level of input from staff from both services, in practice, the staff members from the Mental Health Service appeared to take a leading role in decision-making processes affecting the child and family. This was especially evident in cases where the families did not adhere to the treatment. Staff from the Mental Health Services initiated legal processes against parents who failed to follow the recommendations of medical professionals with regards to their child’s treatment schedule. “If the family refuses the treatment, there needs to be a legal intervention. The right to life is a right, you cannot decide if you are the parent that you will not bring the child. The child has a right to receive treatment", one of the psychologists argued.

Psychosocial care as secondary to medical care

The staff providing psychosocial care emphasized the importance of the services they provided to children and families, but in many cases, they considered this service as secondary to the medical treatment children required. As one of the psychologists we interviewed argued, "The most important thing, the main issue, is the physical disease, we can only support and help".

In some cases, the primacy of medical care was justified based on the need to provide urgent medical attention to children in delicate health condition. However, the predominant role of medical professionals in the decisions made about the children's care was seen in other types of cases as well. As one of the psychologists explained, "there are two psychologists who work specifically in the area. Our colleagues [referring to the medical professionals] do not support them. The same things happens to the social worker, we have to do our work after the medical team has finished theirs".

MDT (multidisciplinary team) working is mentioned as a component of the cancer care provided to children in these units, but according to the staff providing psychosocial care, it is rarely carried out in practice with members of the Mental Health and Social Work service. Our observations of MDT meetings and other meetings carried out to discuss patient cases confirmed this as these rarely involved representatives from the Mental Health and Social Work service. As one of the social workers said, "They [medical team] call us for the difficult situations, dysfunctional families, lack of acceptance of treatment, domestic violence". According to one of the psychologists, “they call us in cases related to the adherence and acceptance of treatment, mainly acceptance from the parent’s perspective”.

As a consequence, the staff we interviewed do not see psychosocial care as an integral part of the services delivered to children with cancer and their families; they see themselves as working in parallel to their medical colleagues. “We normally move aside in terms of the child’s disease. The medical team sets the priorities; they say the child will be cured by doing this or that. We, on the other hand, think what we can do so the family can do this or that”, one of the social workers explained.

The institutional factors framing psychosocial care

The Mental Health and Social Work services are featured as examples of the wide range of services the hospital is able to provide to children and their families. Each service has its own office with dedicated members of staff. When we take a closer look at service delivery, however, we are able to see that the resources allocated to these teams are not enough to deal with patient demand. Not all staff members work full time and the number of patients requiring psychosocial care exceeds the number of cases members of staff are able to cope with. As a consequence, members of staff feel overworked, and all of our interviewees mentioned having to deal with high levels of stress. As one of the social workers argued, “we are a service that in relation to the number of staff members and the demand from patients, we are too small, there is always more work required”.

This lack of institutional support has a direct effect on the number of patients psychologists and social workers in the hospital are able to see and on the quality of the care they can provide. Our observations in in-patient wards and outpatient areas pointed to the fact that routine and early screening for psychological distress and social needs of patients and family members is not carried out. Children receiving oncology treatment and their families only see staff from the Mental Health and Social Work service if medical professionals make a referral because they think there is some sort of “problem”. Psychosocial care, therefore, is not considered an integral part of the delivery of care for oncology patients, it is “reserved” for cases where medical professionals consider that the patient and family members are having difficulties coping with the disease, treatment, financial demands, etc. The criteria used to refer patients are not standardized. This decision is left up to the individual judgment of the doctor in charge of the child’s care.

This has consequences on the types of decisions that are made with regards to the child’s care. As one of the psychologists explained, “the professionals in mental health and social work, we think our participation in the decisions that have to do with this pathology [cancer] are fundamental. When the interdisciplinary working fails, one ends up using inadequate strategies, like the inadequate discharge of a patient who is fit to go home, but whose living conditions are not suitable”. The holistic view of patient and family needs is, therefore, lost in practice.

Discussion

Standards of psychosocial care have been developed at an international level, and there is widespread agreement that psychosocial care should be an integral component of the care offered to oncology patients and their carers (Carlson and Bultz, 2003; Holland et al., 2011; Jacobsen and Lee 2015; Northouse et al., 2012). In practice, however, patients are not always screened for psychological distress or social needs at an early stage in treatment, they might not be offered psychosocial care during hospital treatment, and might encounter even more difficulties while attempting to access these services in their communities (Kazak et al., 2011; Mehnert and Koch, 2005). As a consequence, patients' psychological and social needs are not always met (Gil Deza et al., 2014; McIllmurray et al., 2001). This can have negative effects on their experience of treatment and quality of life.

Our ethnographic exploration of the delivery of psychosocial care to children with cancer in one public children's hospital in Argentina expands the findings of previous studies on this topic. Similarly to Mehnert and Koch (2005), we found that many patients are not screened for psychological distress and psychosocial care is not integrated in clinical practice (Mehnert and Koch, 2005). Our examination of the delivery of psychosocial care from the point of view of the providers pointed to the barriers in service delivery they encounter on a daily basis. By looking at their practices, we were able to see that the existence of a psychosocial care team does not mean that psychologists and social workers will create joint working dynamics or deliver care as a team. Furthermore, it does not mean that psychosocial care will be integrated in the decision-making processes affecting patients or the services they are offered. One of the 15 standards for the psychosocial care of children with cancer and their families established by the PSCPCC centers on the integration of psychosocial professionals in pediatric oncology care settings and the establishment of open communication and collaboration between medical and psychosocial care providers (Wiener et al. 2015a). In our study, despite the existence of a fully formed psychosocial care team, doctors continued to be the main professional group in charge of the patient's care and, psychosocial care was requested when the doctors deemed it necessary. The standards proposed by the PSCPCC advocate in favor of a more prominent role for psychosocial care professionals, where they offer consultation on the psychological management of patients and family members to the rest of the pediatric oncology team (Wiener et al. 2015b).

We found similar barriers to those cited in other studies such as financial constraints and insufficient members of staff to deal with patient demand (Mehnert and Koch, 2005; Weis, 2015). Our study has shown that in the face of these barriers, psychosocial care providers implement a series of strategies to provide services, including working longer (usually unpaid) shifts, not screening patients, and providing services only to "serious cases". Lack of standardized screening means that most patients will not receive any type of psychosocial care and “serious cases” can be missed (Jacobsen and Lee 2015).

The lack of screening and potential missing of “serious cases” means that most children with cancer and their families are left to deal with the psychological and social consequences of cancer and its medical treatment on their own. In previous publications, we have highlighted the main problems experienced by families seeking pediatric oncology treatment in Argentina. These problems include dealing with financial difficulties produced by having to relocate or travel for treatment, purchasing medication or medical supplies or the loss of employment of the parent accompanying the child during treatment (Vindrola-Padros and Whiteford 2012; Vindrola-Padros and Brage 2017). Parents and siblings are not screened routinely and therefore lack psychosocial support (Vindrola-Padros 2012). Furthermore, children receiving cancer treatment rarely receive assistance to maintain academic continuity or facilitate school reentry (Vindrola-Padros 2012).

The findings discussed in this article should be understood in relation to the limitations of the study. This is a single-site study with a small sample of psychosocial care providers. Our analysis is limited to the views and experiences of a small number of professionals and cannot be generalized. Future research needs to be carried out in other hospitals to identify common themes in the delivery of psychosocial care across the country. Furthermore, the views of doctors, nursing staff, patients, and their carers need to be taken into account.

Conclusions

Our ethnographic study of one children's hospital in Argentina has highlighted the barriers psychosocial care providers encounter while attempting to deliver services to children and their families. Weis has argued that "psychosocial care must be delivered to every patient who needs it" (2015:85). Our findings indicate that this does not always happen in practice. Further work needs to be carried out to fully integrate psychosocial care in cancer care and ensure this type of support is available for all patients and their families. The standards proposed by the PSCPCC (Wiener et al. 2015b) can be used as a starting point in the development of national health policies. These policies will need to highlight the importance of interdisciplinary collaboration, early screening of psychosocial needs, assessment of the financial burden of treatment (and in many cases, travel to obtain treatment), psychosocial care for parents and siblings, support during follow-up and assistance with academic continuity.

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