



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



Eugenia Brage, BA, MA ^a, Cecilia Vindrola-Padros, BA, MA, PhD ^{b,*}

^a Facultad de Filosofía y Letras, Universidad de Buenos Aires, CONICET, Buenos Aires, Argentina

^b Department of Applied Health Research, University College London (UCL), London, UK

ARTICLE INFO

Article history:

Received 25 August 2016

Received in revised form

21 February 2017

Accepted 8 May 2017

Keywords:

Psychosocial care

Cancer

Children

Ethnography

Argentina

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.

© 2017 Elsevier Ltd. All rights reserved.

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

* Corresponding author. Research Associate, Department of Applied Health Research, University College London (UCL), 1-19 Torrington Place, London, WC1E 7HB, UK.

E-mail address: c.vindrola@ucl.ac.uk (C. Vindrola-Padros).

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; Surbone et al., 2010; Wiener et al., 2015a,b). 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).

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., 2015a,b). 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., 2015a,b). The main aim of these standards is to guarantee "universal access to psychosocial support and intervention for patients and family members" (Wiener et al., 2015a,b: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.

1. 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) (Moreno et al., 2013), however the survival rate is much lower (61% at five years after diagnosis) (Abriata and

Moreno, 2010; Moreno et al., 2013). 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 80%) 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).

1.1. 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

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	Jacobsen et al., 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., 2015a,b

Download English Version:

<https://daneshyari.com/en/article/5567741>

Download Persian Version:

<https://daneshyari.com/article/5567741>

[Daneshyari.com](https://daneshyari.com)