Transitioning HIV-infected Children and Adolescents into Adult Care: An Italian Real-life Experience

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As young people living with HIV age, transition to adult care is increasingly required. The aim of our study was to describe how a care transition program was developed in an HIV adult clinic in Genoa, Italy. This is a descriptive study including 45 HIV-infected patients who participated in the transition process from a pediatric unit to an adult Infectious Diseases Unit, which started in 2000. A dedicated day, patient-customized environment, psychological support, and all health services in one site were provided. In 2014, a survey form was created to investigate the efficacy of the transition. At survey compilation time, 38 patients (84.4%) were retained in care, 2 were lost to follow-up, 2 were transferred to another adult clinic, and 3 had died. We highlight the importance of planning the transition process and the role of the interprofessional team to guarantee a successful transition for HIV-infected children and adolescents.

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Thanks to the introduction of combination antiretroviral therapy (cART) with the consequent improvement in quality of life and life expectancy, young people living with HIV continue to age and, consequently, the need to improve services, policies, and programs intensifies (Bamford & Lyall, 2015). In addition, many perinatally and behaviorally infected adolescents are now transitioning to adult care (Cervia, 2013). The program for transition of care provides the purposeful, planned movement of adolescents and young adults with special health needs, such as HIV, from child- to adult-oriented health

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care systems (Bamford et al., 2015). Transition is a multifaceted, active process that attends to medical, psychological, and educational or vocational needs (Reiss & Gibson, 2002). The transition process needs to be smooth and planned in advance to improve the chances of success. Uninterrupted services produce better health outcomes; planning for transition needs flexibility and high-quality interactions between children/adolescents, service health providers, and their family members/caregivers (AIDSTAR-ONE Project, 2012). A limited number of research- and practice-based resources are available for health care providers to help with the transition process (Boudreau & Fisher, 2012).

Common barriers to transition of care have been recognized; many of these are woven together, making it difficult to analyze them separately, but they play an important role in the success or failure of the transition process (Abadi & Rosenberg, 2011; Weiner, Kohrt, Battles & Pao, 2011). Economic, logistic, educational, and psychological barriers, including lack of communication between pediatric and adult medical teams (Dowshen & D'Angelo, 2011), the hesitancy of patients/caregivers to leave pediatric care, stigma experiences (Weiner et al., 2011), and lack of transition training and specific clinical guidelines have been identified (Betz, 2004). Vijayan, Benin, Wagner, Romano, and Andiman (2009) identified three challenges to transitioning and caring for young people living with HIV: (a) adhering to complex medication regimens, (b) negotiating the patients' sexual worlds, and (c) maintaining stable places in frequently disorganized social environments due to loss of a family member. Other challenges during the transition process of patients with vertically transmitted HIV infection have been the clinical and psychosocial impact caused by disclosing the diagnosis of HIV to the child/adolescent, disease awareness and acceptance, self-efficacy, and cART adherence (Committee on Pediatric AIDS, 2013; Zanoni & Mayer, 2014). In the majority of studies concerning the transition process, the importance of using an interprofessional approach and providing HIV care in settings where patients could receive all services in one location from an interprofessional team was constantly highlighted (Horberg et al., 2012; National Guideline Clearinghouse, 2011). For most patients in Western countries, HIV infection can now be treated as a chronic disease; 64,898 people live with HIV infection in Italy, of whom 973 (1.5%) are between 0 and 19 years of age. In the Liguria region (Italy), HIV has infected 3,150 people (4.85% of the Ligurian population), of whom 2,172 live in Genoa, the main city of the Liguria Region (Camoni et al., 2013). The aim of our study was to describe how a transition-of-care program has been developed in an HIV adult care unit in Genoa, Italy.

Methods

This is a descriptive study including all HIV-infected patients who participated in the transition-of-care process from the pediatric HIV outpatient unit of the Care and Research-based Scientific Institute (IRCCS) Giannina Gaslini to the adult HIV outpatient unit of IRCCS-University Hospital (AOU)-San Martino Healthcare Cancer Institute (IST), both in the city of Genoa, Liguria region, northwest Italy. We defined children as those younger than 12 years of age, adolescents as 12 to 18 years of age, and young adults as 18 to 24 years of age. The transition process started in 2000. An interprofessional team was created, including one nurse in charge of the transition process, two physicians who specialized in infectious diseases, and a psychologist. Before transition, the interprofessional team established a day of the week dedicated exclusively to the care of children, adolescents, and young adult patients, to protect their privacy and ensure an individualized care plan for each patient, taking age into account. During the dedicated day, the waiting room was set up with a playground and toys to create a child-customized environment with a warm welcome and a dedicated space for youth patients.

Before transition, one meeting was organized for patients/caregivers and adult providers to facilitate the gradual change of young patients from pediatric to adult staff. Moreover, an interdisciplinary project was created to provide all health care services to patients in one location during the dedicated day. This project consisted of a network of radiology, nutrition, endocrinology, and neurology consultants to ensure a personalized care process linked to HIV infection with its related comorbidities and cognitive and growth development concerns.