

Migration, minorities and health

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The chronic disease experience at school: an intercultural challenge?

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The experience of living with a chronic illness is a daily reality for more and more children and adolescents (Stanton et al., 2007). This reality affects not only them but their families and those who live more or less connected to them (Clay et al., 2004). Despite this, literature reveals some vulnerability in the definition of chronic disease and also in what concerns the quality of integration for young people. In fact, common diseases such as asthma, diabetes, and arthritis have been repeatedly camouflaged or confused with situations that do not correspond at all to the real health conditions of children/adolescents with these diseases. In a way, this issue is related to the experience of migrant children or belonging to minority groups (Menezes et al. 2012).

School is essential in children and adolescents' life experiences and it is one of the main contexts where misinformation and discrimination take place (Shaw & McCabe, 2008). This means that despite the fact that chronic disease does not involve any kind of intellectual impairment, its physical symptoms and social impacts suggested a lack of acceptance by teachers and peers. It appears that the diversity, and the recognition of the singularities found in this diversity, are not always captured and guaranteed (Clay et al., 2004).

This paper focuses on the analysis of the life experiences of children and young people with chronic illnesses, attending particularly to their challenges in the school setting. Special attention will be given to their well-being and participation behind their experiences of the chronic conditions. Understanding the role of public and political institutions in the adaptation and empowerment of these children is a central goal of this study. In parallel, the meaning of participation and the right for these people will be considered.

This study is based on a mixed methodology, recognizing the potential of plural and hybrid approaches (Greene, Kreider & Mayer, 2004). Data includes i) interviews with parents and educational professionals, ii) focus group discussions with children, iii) questionnaires from children (older than 12 years) and parents and iv) a family narrative.

This study is based on a pluralistic approach allowing for a deeper understanding of the lives of those with chronic diseases, especially the weaknesses and the strategies of those living with a disease. This methodology provided a confrontation of various perspectives and a critical and contextualized analysis of this issue.

In parallel, results revealed the importance of rethinking social paradigms that emphasize both rights and needs. Thus, this paper highlights the importance of recognizing children/adolescents with chronic diseases as citizens who should be treated differently so that their needs are met. An essential point of this work is therefore to understand the experience at school and, moreover, the life experience of people with chronic diseases as a collective issue (Lister, 2007).

On the other hand, it is expectable that this study contributes to decrease the legal vacuum that (mis)guides practices and discourses and, no less articulate, to improve the chronic disease issue in public debates. Finally, this study might also recognize community organizations/associations as new collective actors playing a central role in the transformation of the health field and social integration, particularly in the promotion of people's empowerment and effective democratic rights (Menezes, 2007; Pais & Menezes, 2010).