

Exploring the relationship between barriers to care with parent perceptions of primary care and quality of life in children with Thalassemia major in Kerman in ۲۰۱۵

Background and aim: access to health services and diagnostic-treatment tools with appropriate quality, is one of the most important part of the designed strategies to achieve the Millennium Development Goals, and equal access to health care among different social-economical groups and is one of the main objectives of health policies. Every year more than ۱۰ million children in the world die, therefor child mortality as part of the UN Millennium Development Goals is considered. Thalassemia is the most common genetic disease in the world and one of the chronic diseases that threaten the health of children. Despite the efforts of doctors, administrators and others involved in health care, timely receiving , appropriate and high quality of health care is not guaranteed in any way. The aim of this study was to exploring the relationship between barriers to care with parent perceptions of primary care and quality of life in children with Thalassemia major in Kerman in ۲۰۱۵.

Method: This descriptive-correlativ survey was performed in ۲۰۱۵ and ۱۵۰ children with Thalassemia major accompanying one of their parents participated in it. Data was collected with demographic information, the potential and actually access, (BCQ), (P3C) and (PedsQL) questionnaires. Data was analyzed by using SPSS ۱۹.

Results: Of the ۱۵۰ childrens with major thalassemia, ۴۵,۳% were boy and ۵۴,۷% were girl. Most parents have less education than their diploma. More fathers are also self-employed and worker (۳۶%) and (۳۵,۳%) and the majority of mothers were housewives. (۶۳,۳%) of families lived in city. Mean score of BCQ total scale in the viewpoint of parents was (۶۳,۹۳±۹,۰۸). In the BCQ subscales, parents reported less barriers in knowledge and Beliefs (۷۸,۰۴±۲۳,۴۸) and more barriers in pragmatics (۵۰,۵۳±۱۲,۵۶). The relationship between barriers to care and parent perception of primary care was significant (P-value < ۰/۰۰۰۱). The relationship between barriers to care and quality of life in the viewpoint of children (P-value < ۰/۲۱) and viewpoint of parent (P-value < ۰/۲۰) was significant too.

Conclusion: as regards that a few studies about the barriers to care for children with chronic diseases taken place in Iran, so this study could be an important information base for policy makers, managers, doctors, nurses and other health care team members involved with the families, in the designing of programs and supportive and education interventions to reduce barriers to care.

Key words: Barriers to care , thalassemia major, Parent perceptions of , quality of life , Children



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