Sickle cell disease, the sick Children's care and the experience of their mothers in a Cameroonian hospital

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Objectives

Sickle cell anemia is the most common genetic disease in the world. It is a lethal disease that manifests in children mainly through unpredictable and generalized or localized pain attacks on the body, chronic anemia and higher susceptibility to infections (1,2). Due to the chronic, unpredictable and serious nature of crises, sick children are regulary hospitalised most often after the failure of family initiated self medication (3). These children are assisted by their mothers and sometimes by their sisters during their hospitalisation (4). The culture makes the mother the main responsible for the question of health and education of children which the father is the main financier (3,5,6). The mother overinvests in the care of her sick child. This enables her to blame herself and assmilate the transgression of an ancestral norm that she would have committed (3). However, during the care of the sick child, there is a dyssimetry of knowledgement between the caregivers and the mother regarding the care and the protection of the child against crises. Caregivers hold more effective knowledge than that of the mother in preventing and relieving the child's crises. The mother is therefore relegated to the second rank in the care of her child with the main role answering the questions of caregivers concerning her sick child and his crises. Caregivers find themselves invested with an over protective function for the sick child, putting the mother in the background in the process of caring for her child (7). This research aims to understand how mothers experience this reality induced by the care of their sick child in a hospital environment. The objective is to better understand the subjective relationship that these mothers have with the care of their children in order to better support them, to make them partners of this care and thus to make the family a resource for the sick child and for healthcare professionals.

Participants and Method

Participants and method - We got written permission from the director of a pediatric center in Yaoundé to do research interviews with the mothers. Thus, we integrated the Healthcare team as a trainee psychologist. This allowed a familiarization with the mothers and a direct observation of their behaviors during the care of the child, precious for the understanding of their experience and for the conduct of the research interviews. We presented the object and the research protocol to each mother individually and verbally in the hospital ward, in the presence of the sick child and other mothers and their sick children. After this, we made immediately an appointment with the mothers who agreed to participate in the research concerning the research's interview.

Out of 12 mothers met in a care center for children with sickle cell anemia in Yaoundé, 4 agreed to participate in the research. The mother gave their written consent regarding their participation in this research. This consent guaranteed the anonymity of the data, the confidentiality of the meeting, the lack of jugement concerning the experience of the mothers and their right to accept or refuse to participate in the research.

Research interviews with these mothers took place in their child's care unit in the early evening. The language used for the interviews was French, well understood and well-spoken by the mothers who each have a mother tongue different from French. These interviews took place in the absence of their sick children who were in the hospital ward with the other mothers. We choosed the interviews to understand the mother's experiences regarding the care of their children more than the care themselves. It was a question of understanding the experience of these mothers interacting with the caregivers in a context of co-construction of the interview situation between the mothers and the researcher (8).

The interviews focused on the sick children's care and the way the mothers experience this care and the sickle cell disease. They were recorded and transcribed before being analyzed according to the thematic analysis technic.

Results

Analysis highlights the suffering of mothers in the context of medical interventions, which pay very little attention to their experience as mothers of children with sickle cell anemia. They do not feel very supported and considered as mother by the caregivers. They ask the caregivers to take an interest in their experience. A feeling of guilt experienced by these mothers who remain at home while their child is being hospitalized is evident as well as this demand for attention and recognition by healthcare professionals of their experience and their suffering in a context where the mother is designated as the primary responsible for the illness and care of his sick child. This guilt therefore constitutes, for these mothers, a request for support from caregivers.

Conclusions

The challenge in connection with the results of this research, is to work with families, mothers and children with sickle cell anemia to transform their relationship with the disease (and to their ancestors) so as to reduce this suffering for parents (and children) while respecting their ancestral culture. Working to enable sick children, their mothers and fathers, members of their extended families and their brothers and sisters to share their experience regarding disease and care can be significant in the process of transformation of the suffering caused by the disease in these people. It would be beneficial to set up a space for expression between professionals, mothers, sick children and their brothers and sisters in the care institutions that take care for children with sickle cell disease.

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