

**Participatory appraisal of the illness experiences and
health needs of families affected by
Sickle Cell Disorders in Benin**

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ABSTRACT

Participatory appraisal of the illness experiences and health needs of families affected by Sickle Cell Disorders in Benin: qualitative interview study

Objective: To explore the illness experiences of parents with children affected by Sickle Cell Disorders (SCD), their coping strategies and the difficulties to access health care services.

Setting: Pilot phase of the project of collaboration between Médecins du Monde-Switzerland and the National Programme to fight SCD in Benin. Cotonou (the economic capital) and suburbs; Abomey and several neighbouring rural villages.

Design: Qualitative interview study using the Health Belief Model as a conceptual framework to support and validate the findings. 10 families were interviewed with open-ended questions (setting: 6 urban and 4 rural) followed by two Focus Group Discussions in Cotonou (one with adolescent patients, the other with local association members).

Main findings:

Family caregivers emphasise the importance of knowledge acquisition, psycho-social factors and financial considerations as important issues when coping with illness. The low level of knowledge is a key factor that impedes families to cope well. Benefits of health care management are undermined by the importance of barriers to access (financial, distance, knowledge and human resources). Psycho-social problems are one major consequence of these barriers.

The associations can play a significant role for health promotion and to provide psycho-social support to affected SCD families.

Conclusions:

The question of the availability and affordability of health care are central to the caregivers' adjustments and psycho-social functioning. The perceived benefits of secondary prevention need to be highlighted by facilitating the understanding of its cost-effectiveness.

Associations need adequate training for disseminating sound health promotion messages and should therefore be able to collaborate with public health professionals and the National Programme to fight SCD.