EVALUATING THE EFFECTIVENESS OF THERAPEUTIC EDUCATION FOR SICKLE CELL DISEASE PATIENTS: EXPERIENCE OF A RESEARCH CENTER IN CENTRAL AFRICA, DR CONGO

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Summary

INTRODUCTION

Therapeutic education for the sickle-cell patient is an ongoing process, integrated into care and centered on the patient. It involves organized awareness-raising, information, selfmanagement training and psychological support activities concerning the disease, prescribed treatment, care, the hospital and care environment, organizational information and health and illness behaviors. It aims to help patients and their families understand their illness and treatment, cooperate with caregivers, live healthier lives and maintain or improve their quality of life. It is adapted to the patient's age and to the clinical features of sickle cell disease. There is no cure for sickle cell disease, except for bone marrow transplants, which remain inaccessible to most families in sub-Saharan Africa. Patients and their families must therefore learn to live with the disease. Therapeutic education is a tool for learning skills to improve patients' quality of life and help families acquire knowledge about complications, improve and make intelligible the patient's care pathway, reinforce knowledge of social care among adolescents and adult patients, support adult patients in their family-building project, enable patients and families to verbalize their lived experience.

OBJECTIVES

The aim of this study is to demonstrate the effectiveness of therapeutic education after evaluation with adolescents who took part in 11 workshops, the themes of which were chosen on the basis of a shared educational assessment using the model proposed by the Réseau Ouest Francilien de Soin des Enfants Drépanocytaires (ROFSED) with the support of the NGO Enfants Avenir de Demain.

METHODOLOGY

To assess the effectiveness of therapeutic education for sickle-cell patients, we followed the steps involved in implementing therapeutic education according to the model of the Réseau Ouest Francilien de Soin des patients drépanocytaires (ROFSED) and the recommendations of the Haute Autorité de santé published in 2007. After obtaining informed consent from patients, the following points were closely monitored:

1. Elaboration of the shared educational assessment in which we analyzed the expectations and needs of our patients, with a view to improving the quality of their experience and acquiring self-care skills. Based on our interviews, we defined 11 themes which we divided up between 2023 and 2024.

2. Setting up the program. All our patients opted for group sessions, and together we formulated the skills to be acquired.

3. Session planning and implementation. To make our sessions as effective as possible, we followed the session plan below:

- Subject
- Learning objectives
- Session duration
- Target audience
- Educators
- Teaching method
- Hardware
- Session sequence (with timing)
- Key messages.

4. Assessment of acquired skills. Each session was punctuated by an evaluation of the knowledge acquired. At the end of the program, we proposed a model Google Forms questionnaire of 19 mixed multiple-choice and direct questions, which patients answered online.

RESULTS

We analyzed the responses of 23 patients who participated in 11 therapeutic education workshops during the period from 2023 to 2024, including 12 women and 11 men. The average age was 18 years (16-21) with a sex ratio of 0.9. The level of knowledge of sickle cell disease was good in 47.4%, the personalized follow-up plan was regular in 89.5%, all our patients were able to detect the signs of anemia by themselves (100%), 82.6% know their basal hemoglobin level, 52.6% have not received a blood transfusion, 47.4% have not been hospitalized and 47.4% have been hospitalized 1-3 times, 97.4% are able to manage a painful crisis well at home, 94.7% regularly take hydroxyurea as background treatment, 84.2% are able to plan a healthy, balanced diet, 89.5% are sufficiently informed to make a judicious choice of partner for marriage, 83.3% feel ready to join a patient association or discussion group to combat stigmatization, 72.2% of adolescents feel ready to transfer from paediatric to adult care.

DISCUSSION

This work has the merit of highlighting the effectiveness of therapeutic education for sickle cell patients living in a low-income country after attending group sessions. Our interventions showed an improvement in the level of knowledge of the disease in question. This is supported by Asnani et al. and Shahine et al. who showed a maintenance of the level of knowledge over longer periods. Our study has shown that all our patients are able to recognize the signs of acute anemia on their own, unlike the first author cited above, who has no data on patients' ability to recognize signs requiring management. Our patients know their basal hemoglobin level. This is all the more important given that acute anemia is one of the main causes of death in our patients. Our results show that our patients have acquired the ability to manage a minor pain crisis at home, with a good knowledge of palliative 1 and 2 medications. Our patients have learned to avoid the risk factors that trigger vaso-occlusive attacks by following the preventive measures we summarized in a leaflet called the Ten Golden Rules.

This result is supported by Crosby et al. Our patients were educated on the importance of taking background treatment with hydroxyurea, with a good pharmacological knowledge of the beneficial effects of the drug. Adolescents who attended our workshops understood the need for a guided transition from pediatrics to adult care.

CONCLUSION

Therapeutic education for patients with sickle cell disease is a patient-centred approach that has its place in patient management. It should be offered to all patients or their families, and should be adapted according to age and clinical manifestations. SubSaharan Africa pays a heavy price in terms of complications and mortality from sickle cell disease. Therapeutic education is of paramount importance in making patients the main players in their own care, and enabling them to acquire self-care measures. This work shows that even in a resource-limited setting, therapeutic education interventions can help patients and their families acquire skills that will enable them to live as well as possible with the disease and improve their quality of life.