

Abstract

EXPLORING THE EDUCATIONAL NEEDS OF RELATIVES OF PATIENTS WITH HUNTINGTON'S DISEASE

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Problem

The purpose of this thesis was to investigate the educational needs of family members of patients with Huntington's Disease (HD) and to identify what is lacking in existing information sources available to carers locally that might enhance care for the affected individuals and the quality of life of the carers.

Method

This was done by utilising Focus Groups (FG) methodology, with 25 primary carers of HD patients. As a guide for the FG tool the researcher used data obtained from semi-structured questionnaires administered at two HD international conferences.

Conclusion

The findings of this study provided evidence that education is lacking in all aspect of this devastating disease. They felt the need for more information from when they first heard about HD to the day-to-day care they have to deliver most of the times without given choice. The themes identified in this study were 6: level of support; lack of involvement and participation in the care management; practical aspects of caregiving; avoidance and surviving the search for essential information/ education. The focus was mainly on the last mentioned theme.

The findings of this study hopefully may help to prepare the way for the development of an educational program for these carers, to provide a scientifically based tool to aid people who educate carers in fulfilling these needs and enhance patient care in all aspects of this disease, including prevention of its perpetuation and a better quality of life for these carers.