

CHALLENGES AND OPPORTUNITIES OF HUNTINGTON'S DISEASE IN EGYPT:



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A QUALITATIVE STUDY

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Introduction

Huntington's disease is a rare autosomal dominant neurodegenerative disease. The disease is underestimated in Egypt, with lack of knowledge and awareness among physicians especially young neurologists. This is widely reflected on patients' care and quality of available services. For better understanding of the disease, we need to know more about it and available resources for its management in the country.

Objectives:

The aim of this work is to investigate the challenges facing young neurologist when facing a case with Huntington's disease and exploring possible opportunities.

Methods

Study design and settings

The current study was an exploratory cross-sectional study among young Egyptian neurologists. It used a qualitative approach and was performed in accordance with the Consolidated criteria for reporting qualitative research. CORE-Q. (1)

Sample size and sampling technique

The study population was young neurologists (n= 45), working in 3 university hospitals. The researchers recruited participants using a purposive sampling technique.

Methods

The eligibility criteria for recruitment include: (1) being below 45 years old, (2) both sexes, (3) agreeing to participate and providing written informed consent. The researchers continued the interviews until they reached data saturation, where no new themes, subthemes, or explanations emerged from the interviews (2).

Qualitative interviews

Interview guides were used to facilitate discussion about the challenges facing neurologists when dealing with Huntington's disease cases (Table 1) The participants were asked to report their demographic data. All interviews were audio-recorded and transcribed. Each interview lasted approximately 45–60 minutes. The interview guide was developed after an extensive literature review, with a list of possible questions to assess the perceived barriers in HD management and the suggestions to overcome them. The guide was pilot tested on a sample of four participants, with the required modifications to the guide were done based on the pilot test results. Finally, specific probes identified during pilot interviews were added to the interview guide. However, these findings of pretesting interviews were excluded from the data presented.

Data analysis

The researchers based their data processing on the thematic content analysis technique. This method has been used to generate a rich and comprehensive understanding of complex phenomena (3). The method includes the following steps:

Methods

The researcher read carefully through all the transcripts. After the completion of all the transcripts, a list of similar topics was compiled. Data were grouped according to a theme and sub-themes and field notes were also coded and categorized. The participants' quotations were used to clarify the meaning of the themes and summaries. The analysis was carried out independently by two authors, S.E and M. R. For demographic data, the researchers used Excel 2010 to summarize the quantitative variables using mean and standard deviation, and the qualitative variables using frequency and percentages.

Results

The enrolled neurologist n=46, age range (25–40 years) and had 3–15 years of work experience. About two-thirds of the enrolled participants were females. Thematic analysis of the transcripts of interviews revealed the following themes that reflect the challenges to providing care to patients with Huntington's disease in Egypt, and the strategies that participants thought are needed, either as novel strategies or modifications to create opportunities. The frequently mentioned challenges were: **No available cure.** "I don't feel motivated to know better about diseases with no available cure in absence of MDT and specialized center that improve the quality of life for the patients and families"

Results

Health workforce "lack of coordination between movement disorder specialists, psychiatrists, physiotherapists, and speech therapist.

Late & difficult diagnosis

High cost of investigations

Frequent suggestions:

Funding for research. "we need to start registries and secure funding from international organization as well as raising funds on national levels" his colleague suggested.

Supportive organization. "I don't know where to refer patients and families to get support and help". As we don't have support groups representing patients, We need to start building such nonprofit organizations

Raising awareness.

Conclusion

Early diagnosis and management of Huntington's disease in Egypt depends on spreading awareness about the disease, together with more resources to build up teams and specialized centers to provide the best care for the patients and families. To overcome these challenges, we need more educational and research resources, as well as international collaboration.

References

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