

FAMILY CAREGIVER'S KNOWLEDGE AND PRACTICES OF CHILDREN WITH PHENYLKETONURIA AT ABO- EL REESH HOSPITAL

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Abstract

Background: Phenylketonuria (PKU) is a chronic disorder which needs family caregivers' daily effort to deal with the child's disabilities and to maintain a special rehabilitation and diet program. Family caregivers play a pivotal role in the management of childhood Phenylketonuria. **Aim of this study:** To assess family caregivers' knowledge and self-reported practice regarding Phenylketonuria at the Child clinic of metabolic disorder of the Social Preventive Medicine Center, Abo El-Reesh, Cairo governorate. **Design:** A descriptive research design was utilized to fit the purpose of the study. **Setting:** The study was conducted at the clinic of metabolic disorder of the Social Preventive Medicine Center, Abo El-Reesh hospital, Cairo governorate. **Sample:** A sample of 140 family caregivers and their children with Phenylketonuria were included in the study, and the data were collected in six months from October 2011 till March 2012. **Tools for data collection:** Data was collected using structured interviewing questionnaire, knowledge sheet, and practice sheet (self reported questions) for the family caregiver's home practices regarding PKU. **Results:** The study indicates that nearly one quarter of the family caregivers have unsatisfactory total knowledge scores, more than half of the family caregivers have satisfactory total knowledge scores, while minority of the family caregivers have good total knowledge scores. The majority of the family caregivers had a poor level of practice, while only (4.3%) of them had got good level of the practice score, while (3.6%) of the caregivers had fair level. A highly statistically significance correlation was found between the family caregivers' total knowledge scores and their total practices scores which means that the family caregivers' knowledge had an effect on their practices, as when family caregivers have a good knowledge level regarding their children conditions; this will improve their practices regarding care of their children with PKU. **Conclusion:** The study concluded that, the family caregivers had poor level of knowledge and yet the vast majority of children still achieved poor dietary control and poor care. **Recommendations:** Based on the study results it is recommended to develop a training program regarding Phenylketonuria to provide them with knowledge and skills to help them in caring for their children at home.

Key words: Family caregivers, children and Phenylketonuria

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