

Awareness of Renal Nurses Regarding Identifying and Educating Patients and Families with Inherited Renal Diseases

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Background: There is a high prevalence of genetic disorders in the United Arab Emirates. The increased awareness about the importance of early identification of patients with genetic disorders such as inherited renal diseases has provided the disorders with a high level of prominence in primary health care settings. Nevertheless, there is empirical evidence indicating that there is a low level of understanding regarding inherited diseases among nurses.

Aim: This study is aimed at exploring how renal nurses identify patients at risk or those with inherited renal diseases and the renal nurses' awareness about support services available for patients with these disorders and their families.

Method: The researcher used a descriptive phenomenological study approach, and semi-structured face to face interviews to collect data from four renal nurses working in the hospital. This study has been carried out in Seha Dialysis Services (SDS) unit in one of the main hospitals in Abu Dhabi, United Arab Emirates, a country that has one of the highest rates of genetic disorders in the world and consanguineous marriages as high as 50%. A thematic analysis was used where themes emerged from the data collected, the themes in this study were, prevalence of renal genetic diseases, nurse identification of renal genetic diseases and awareness of genetic services available.

Result: Polycystic kidney disease, Alport disease and glomerulonephritis were identified by the participants as the most common disorders in the UAE. All the nurses had limited knowledge about the most common types of inherited renal diseases, identification of patients with the conditions and about genetic care services available for these patients. The nurses highlighted the need for genetic training so as to increase their general awareness about the diseases. In addition, it was found that in some cases, diagnosis of inherited renal diseases is usually accidental when carrying out diagnostic and screening tests for other reasons.

Conclusion: The findings made in this study indicates that the renal nurses working in Abu Dhabi SDS units have limited knowledge regarding the causes, signs and symptoms, management, support services and diagnoses of inherited renal diseases which is crucial in providing information to patients on the possible outcomes of a genetic disorder. The findings presented in this descriptive study indicate that there is need for providing genetic training and education to renal nurses with regards to inherited renal disorders and awareness of existence of genetic services and accessibility of genetic services to the public. More research is also needed in exploring and expanding the study to a larger population in different settings. Genetic education workshops for the nurses and a renal genetic data base to keep track of prevalence of renal genetic diseases.

Key words: Inherited renal diseases, renal nurses, awareness, content analysis, consanguineous marriages, prevalence, patients, knowledge, genetics

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Session: Poster Session D

Time of Session: 11:00 - 12:30

Scope of plan both educational and operational

Educational	Operational
Curriculum 1-5 Organized Sessions	Create a renal genetic data base (sample excel sheet in Appendix 5)
Session 1. Overview of genetics	All nursing unit managers to update all genetic conditions in their units
Session 2. Patterns of inheritance	Inform/Advertise to all SDS staff about the program
Session 3. Renal genetic diseases	Inspire all strengthening forces for this implementation
Session 4. Family history taking and Pedigree	Set up evaluation plan

SEHA Dialysis Services' Renal Genetic Diseases Data-Base

Patient MRN	Diagnosis	Autosomal Dominant	Autosomal Recessive	Consanguineous (Y/N)	Other family members affected