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

Faduma Sharif; Nesreen Al Qaissi; Anne Cullimore; Pauline Byers; Carol Greenway; Deborah Dowsett; Michelle Bishop; Marie Richards; Nick Richards

Introduction

- A small purposive study carried in one of the renal units in Abu Dhabi, UAE

- To explore how renal nurses identify patients with or at risk of inherited renal diseases

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Background

- The indigenous population
  - High level of consanguinity rates
  - As high as 50%
  - High rates of single gene disorders

- Existing evidence indicates that genetic and congenital disorders account for a huge proportion of morbidity and mortality in the UAE

Background

- Certain genetic disorders such as inherited renal diseases are common and genetic services in the country are intermittent, selective and to a huge extent inadequate

- Premarital screening for single gene disorders and newborn screening

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Background

- Genetic diseases are the fourth leading cause of death in the UAE (WHO, 2012)
- UAE ranked 6 out of 193 countries for the prevalence of congenital defects
- More than 270 genomic diseases in the UAE

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Background

Common genetic disease are:

- High prevalence within the pediatric population
- Siblings in the same family

Example

- Hemoglobinopathies
- Single gene disorders

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Background

- The Center for Arab Genomic Studies has instigated a pilot project to establish a database catalogue of genetic diseases in the Arab World

- UAE Genetic Disease Association

- International Genetic Disease award and conference to increase awareness

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Awareness of Genetic Diseases among Nurses

- Genetics is relatively new subject in the field of Nursing
- Despite scholars recommending the topic be included in the nursing curricula about six decades ago
- Consequently, there are few studies evaluating nurses' knowledge of genetic diseases
- No studies found assessing renal nurses' awareness about inherited kidney diseases
- The studies reviewed indicate that nurses working in various health care centers have inadequate knowledge with regards to genetic diseases

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Method

- Methodology: A qualitative purposive study
- Sample: Four renal nurses
- Data Collection: A face-to-face semi-structured interviews with three broad open-ended questions

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Objectives

- To explore how renal nurses identify patients with inherited renal disease

- To assess nurses' awareness of support services available to patients with or at risk of inherited renal disease and their families

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Results

Three major themes emerged from the data:

1. Nurses' knowledge of inherited renal diseases, including most common causes and prevalence

2. Needs for services and education for both nurses and patients and for expert specialty in genetics

3. Identification of patients with renal genetic disease

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Results

- When asked about the most common types of the inherited renal diseases and the causes
- Nurses highlighted that pckd: Alport's disease and nephrotic syndrome were the most common disorders
- Three nurses confirmed that they had encountered patients where their relatives had polycystic kidney disease or nephrotic syndrome
- Two participants gave some incorrect responses which indicated limited knowledge about inherited renal diseases

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Data Analysis

- Conventional thematic content analysis

- Ethical approval: Granted by the Ethics Committee of De Montfort University Faculty of Health Sciences Research Committee, UK.

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Results

- All of the participants believed the main reason for a high rate of inherited renal diseases in the UAE is due to consanguineous marriages
- One highlighted that the deep rooted consanguineous marriage trends may be due to culture
- But they were not able to explain that consanguinity exposes risk of high autosomal recessive disorders

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Results

Of the possible ways of identifying patients with inherited renal diseases all the nurses highlighted:

- use of family history
- patient medical files
- patient history (interviews)

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Results

- The participants highlighted that diagnoses of patients with an inherited renal disorder is usually accidental

- During routine medical checkups such as ultrasound exams, cysts on the kidney might be discovered and then further tests run

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Results

- Nurses are not aware of services except for premarital screening and new born testing carried
- All the participants identified a need for more genetic services in the UAE
- In addition, the responses indicate that the nurses are open to genetic education and have acknowledged the need for educating nurses about inherited renal diseases

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Recommendations

Scope of plan

- Educational
  - Expand on genetic workshops
  - More comprehensive genetic workshops
  - Focus on the patterns of disease inheritance

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Recommendations

- Operational
  - Create a renal genetic database (excelsheet)
  - Explore on services available to the public and increase awareness of these services to the nurses and patients

More research development educational material that is compatible with the culture of the UAE society

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Conclusion

- On the whole most nurses had limited knowledge of genetic disorders and patterns of inheritance
- Need to provide genetic training and education to renal nurses with regards to inherited renal disorders
- More genetic services and an expert in genetics
- Similar findings in the literature

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Conclusion

- Most of the studies confirmed
  - Limited knowledge of the nurses,
  - No role in genetics
  - Need for education and more services
  - Specialist in genetics
  - More research in different settings and larger samples

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