



Service Priorities and Programmes
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So Rare, Who Cares? A Study of Stress and Coping of Parents of Children with Rare Diseases in Hong Kong

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Introduction

Rare disease is a group of chronic and complex genetic disorders characterized by a very low prevalence rate. About half of new cases present at birth and affect children for physical or mental impairments, severe disabilities, and even life-threatening. There are scant researches conducted concerning families of children with rare diseases on the psychosocial impacts and the ways of coping in either Western countries or Chinese societies.

Despite Hong Kong is an affluent international city, its protection and support for people with rare diseases lags behind other Asian countries. The Hong Kong government has not established a definition for rare diseases or set up any policies for rare disease management. The special needs of people with rare diseases and their families are undermined in the current healthcare and social welfare systems.

Objectives

- 1) To examine the stress and difficulties encountered by the parents in take care of their children with rare disease in Hong Kong;
- 2) To study the ways of coping employed by the parents
- 3) To inform healthcare professionals and policymakers about the needs of these families and to make recommendations on services and support for them

Methodology

A descriptive qualitative research approach is adopted to investigate the experience of the parents in taking care of their rare disease children. Sixteen parents from twelve families were recruited through purposive and snowball sampling. In-depth semi-structured interviews were conducted face-to-face. The interviews were audio-recorded and verbatim transcribed. Thematic analysis was performed with the Supportive Care Need Framework, Stress and Coping Theory and the Family Adjustment and Adaptation Response Model employed as the guiding frameworks.

Result

An Integrated Family Adjustment and Adaptation Model is developed in the study. The major stresses encountered by the families are identified i.e. Lack of knowledge and

awareness on the part of healthcare professionals, delay in diagnosis, huge financial stress on the expensive drug fees and rehabilitation equipment. Family relationships problems, psychological impact, depression and suicidal ideation are pervasive among the parents.

Information on the Internet, patient support groups, family resources, community resources and support from schools are the five most important coping resources utilized by the families.

The study demonstrates that rare diseases bring enormous stress to the families.

Many of the challenges are intrinsic to the present healthcare system.

Recommendations were made in the study to appeal for the support of the Hong Kong government and healthcare professional for supporting the rare disease patients and their families.