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A search for commons in rare diseases - A systematic review of studies on stress and coping of families with children with rare disease

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Introduction

Rare diseases are groups of disorders which are chronic and complex genetic in nature, often diagnosed at infant or childhood. Rare diseases usually manifest with severe disabling, physical and mental impairments and sometimes life-threatening. Due to rarity of the illnesses, the adversities of the patients and their families are largely unheard in the society. Literature search reveals that studies on psychosocial stress and copings of rare diseases of patients and families are scanty in western countries and even none in Hong Kong.

Objectives

A systematic review was conducted to review recent researches on the stress encountered by the families with children with rare diseases, and examine the coping strategies that families have adopted to overcome the hardship in western and Chinese societies.

Methodology

The systematic review was undertaken on original quantitative or qualitative research studies on the stress and coping for the families written in English or Chinese. The search was conducted based on major research electronic database also the Chinese database in Taiwan and the mainland China, supplemented by hand search from January 1999 to Sept 2014. Finally 20 English and 5 Chinese articles were found. All the studies were published after 2005.

Result

Altogether 20 English and 5 Chinese articles were found. All the studies were published after 2005. Six major themes for stress and difficulties: i) lack of knowledge and delay diagnosis; ii) psychological and emotional stress; iii) caring of children; iv) spouse and family relationships; v) lack of social resources and financial stress and vi) schooling and social stigmatization, and four key areas of coping: i) information and support from internet source; ii) social support and external resources; iii) family restructuring and iv) religious beliefs were identified. Some distinctive features for

Chinese families were also recognized. Despite of the rarity and heterogeneity of rare diseases, commonalities in the problem encountered and ways of coping were found across countries, western and Chinese cultures. This review study contributes to provide solid evidence-based information for researchers and social work practitioners to formulate their framework to assist the rare and vulnerable families. For the author, the study laid down a firm keystone for his follow up research for the undermined rare diseases families in Hong Kong.