UNEARTHING CHALLENGES PARENTS WITH CHILDREN DIAGNOSED WITH CHRONIC /LIFE THRETENING ILLNESSES ENCOUNTER

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AIM

.To understand the challenges that parents with children diagnosed with chronic/ life threatening illnesses go through.

Specific Objectives

- To identify common challenges parents with children diagnosed with chronic/life threatening illnesses encounter.
- To highlight societal perceptions towards children suffering from chronic/life threatening illnesses.

Introduction

- A chronic illness will have both direct and indirect effects on the family members and their relations.
- In Malawi most people live a communal life, where there is a lot of dependency from immediate and extended family members.
- Once a child is diagnosed with a chronic/life threatening illness, it is not unusual for the family members to feel anger,denial,self-blame,fear,shock,confusion and helplessness.

Background

- Queen Elizabeth Central Hospital(QECH)in Malawi is the biggest referral hospital with well integrated palliative care services for children since 2002.
- Children and their families with chronic illnesses are referred to palliative care service for symptom control ,counselling on disease understanding ,psychosocial support and rehabilitation among others.

Design

- The data used was collected at Queen Elizabeth Central Hospital-Umodzi children palliative care unit.
- 34 chronically ill patients and their guardians were recruited ,out of this sample ,21 were males and 13 females between the period of July and December 2015.
- The study captured the views on the challenges the parents with children living with chronic/life threatening illness face.
- 25 respondents were given questionaires,6 people were involved in focus group discussion and 3 were interviewed using in-depth interviews.

Limitation

- The study did not take into consideration the education status of the families of the children with chronic/life threatening illness, in an effort to explore their understanding on the disease condition of their children.

Results/findings

- The study revealed that the society has the perception that chronic/life threatening illnesses are associated with witchcraft. People in the community link disease that take long to recover to an act of sorcery. It is assumed that people will use a child as a sacrifice for one to accumulate wealth/to get rich.
- The community members commonly blame the parents or the family members of the chronically ill child of having a hand in the child's illness, and sometimes this blame game is amongst family members, i.e. it could be between the mother of the sick child and her brother(an uncle to the sick child)

- There was also a perception of stigma attached to chronic/life threatening illness, which result into parents with children diagnosed with life threatening illness avoiding public appearances, because of shame with what people will say: because their children look different from the rest of the children.

Conclusion/Lesson learnt

- Parents living with children with chronic/life threatening illnesses face myriad challenges such as social isolation and stigma. These challenges lead to poor emotional healthy. The society show less commitment of support.

Recommendation

- Promoting counselling services,by ensuring that palliative care units have well trained child counsellors to promote disease understanding to children and their parents as well as society at large. A lot of children palliative care units have no trained child counsellors.

Reference.

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