Stressors and Coping Patterns of Children Suffering From Chronic diseases and Their Mothers

Protocol

Submitted for Partial Fulfillment of Master Degree in

Pediatric Nursing

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Introduction

A chronic disease is a physical condition that lasts longer than 3 months and is of sufficient severity to interfere with the child's ordinary activity to some degree. The most chronic conditions include asthma, epilepsy, congenital heart disease, diabetes mellitus, arthritis, cystic fibrosis, chronic renal failure, malignancy, cerebral palsy and spina bifida **(Rudolf et al., 1999).**

The impact of chronic diseases on a child depends largely on his or her developmental level. However, the chronically ill child is two to three times more likely to experience emotional, behavioral, educational difficulties, low self esteem, impaired self image, anxiety and school dysfunction **(Wong et al., 2003).**

The chronic disease of a child affects family on a number of levels including practical, social and psychological as altered daily routines through recurrent patient visits and hospitalization. Anxiety, depression, guild and grief are common problems particularly for mothers, while sibling reacts to chronic illness by anxiety, embarrassment, resentment and guilt **(Rudolf et al., 1999).**

Stress is a condition of situation that imposes demands for adjustment **(Haziniski, 1992)**. So stressors experienced by parents of children who are critically ill can be categorized as at time of diagnosis include shock, disbelief while during developmental transitions many parents experience chronic sorrow and while meeting the ongoing health care needs which are time consuming, rigorous, financial burden is

another major stress and hospitalization create stress because they interrupt normal routines **(Perkin et al., 2003).**

Coping is a problem solving strategy used by person to manage the stressors by taking action **Mahat (1006)**, so infant respond to stress with crying and cope by sucking fingers, toddler react to stress with increased physical activity and cope by regression, preschoolers increased verbal skills allow them to cope with stress by seeking information while adolescent react to stress by anxiety, fears and cope by denial **(Slota et al., 1998)**, and generally coping patterns include shock, denial, adjustment, reintegration and acknowledgement **(Wong et al., 2003).**

The role of the nurse can be summarized as outcome identification and planning, helping family to adjust to a child condition, encourage optimal growth and development, reducing anxiety about procedures and treatment, promoting self care, preventing social isolation, aiding caregivers acceptance of the condition, planning for home care **(Marks et al., 1998).** The nurse can help families also to realize their abilities and strengths, identify problems and stresses, develop problem-solving strategies and identify new coping strategies **(Wong et al., 2003).**

Aim of the Study

The aim of the study is to assess stressors and coping patterns of children suffering from chronic diseases and their mothers.

Research Questions?

1) What are the stressors facing both chronically ill children and their mothers?

2) What are the coping patterns of a chronically ill children and their mothers?

3) In there a relationship between the chronically ill children's characteristic and their coping patterns and the same for their mothers?

Subjects and Methods

Research design:

Descriptive study.

Setting:

The study will be conducted at inpatient and outpatient pediatric departments of children's hospitals affiliated to Ain Shams University Hospitals.

Sample:

The sample will include all available chronically ill children and their mothers attending the above mentioned setting over a 6 months their mothers attending the above mentioned setting over a 6 months period regardless their gender, educational level with age that ranged from 6 to 18 years old. All available accompanying mothers will also be included regardless their educational level, job, ages.

Tools and technique of data collection:

I. Pre designed questionnaire (by interviewing) will be developed by researcher after reviewing relevant literature. It will be written in simple Arabic language to suit level of understanding of both chronically ill children and their mothers to collect data regarding:

1. **Characteristic of the chronically ill children include:** age, sex, educational level, rank, residence, child's present health

status, duration of illness, present treatment and frequency of Hospital admission.

2. **Characteristic of mother of chronically ill children include:** age, educational level, occupation and characteristic of the family.
3. Knowledge of children's if they are old enough to verbalize their understanding and there accompanying mother's regarding chronic disease of the children in terms of definition, causes, sign and symptoms, types and treatment.
4. Perceived stressors and ways of coping.

II. Coping scale:

To asses coping of the subjects.

III. Psychometric assessment:

To assess anxiety and depression of the study subjects.

Operational design:

A. A pilot study:

A pilot study will be conducted to evaluate the effectiveness of the study tools which will be used, according to its results the necessary modification will be done.

B. Field work:

The study will be conducted for 5 days/week over a 6 months period, the researcher will be available from 9 am to 12 pm, each mother and her child will be assessed individually for 30 minutes, aim of the study and its expected outcome will be explained for each subjects, the researcher will introduce her self to the chronically ill children and their

mothers, anonimenity, confidentiality and privacy of the study subjects will be secured.

Statistical design:

Data obtained from the study will be organized, tabulated and analyzed, using the appropriate statistical methods and tests.

Administrive design:

Approval to conduct the study will be obtained from administrators of the previously mentioned settings.

Results, Discussion, Conclusion and Recommendations: will be stated as revealed from the study findings.

- **Summary**
- **References**
- **Arabic Summary**

References

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Introduction

Although the diversity in terms of clinical characteristics, causes and treatment, the chronic health conditions have a lot in common with regard to their impact on the affected children, families and the specialized needs that they present to the healthcare system. The affected children are at much higher risk of disruptions to their social, emotional, behavioral and educational achievement with effect that may last a lifetime ***(Miller et al., 2004).***

The chronically ill child is three times more likely to experience emotional, behavioral and educational difficulties. Low self-esteem, impaired self image, behavioral problems, depression, anxiety and school dysfunction are all common problems occur as a result of the child's own reaction to his/her chronic disease or the reaction of parents, peers, professionals and society as a whole ***(Rudolf and Levene, 2004).***

The impact of a chronic illness on a child's life will be determined by a number of influencing factors including age at diagnosis, stage of development, gender, personality, temperament and coping styles. The characteristics of the chronic condition, including nature of onset, disease trajectory, effect on; appearance, daily functioning and behavior in addition to the care required. The impact on the child will be influenced also by parental (mainly mother) response and coping patterns ***(Cooper, 2006).***

The potential impact of childhood chronic illness on parents and families has delineated a myriad of stressors that parents may experience, including financial stress, role strains, separation, adjustment to the various components of the medical system, interruptions in daily routines and plans for the future and the general uncertainty with regard to the child's prognosis. All of these possible experiences may lead directly and indirectly to anxiety, depression, post traumatic stress, hopelessness and feelings of loss of control ***(Kazak et al., 2003).***

Children with chronic diseases are confronted with a specific interpersonal situation as they have to cope with the fact that, their condition is not only affecting their own life but also that of their parents and siblings. Children also face the challenge of coping with the unique demands of their chronic condition, while coping at the same time with the developmental tasks associated with their particular age group ***(Meuleners et al., 2002)***. Children with chronic illness are presented with unique problems in school, where they may encounter a range of academic, social and emotional difficulties ***(Shiu, 2004).***

Coping strategies used by children with chronic illness will depend upon their personal characteristics, which include level of confidence, self-esteem, usual coping style, view of the world, past experiences, developmental stage, cognitive ability, family structure and dynamics and how parents, family and friends perceive and cope with the condition ***(Mu, 2005).***

Caring for children with chronic conditions is a challenging, and time-consuming. It requires a commitment to service beyond that required for routine ambulatory pediatric care. Increased knowledge about children, interpersonal communication and organizational skills are necessary to provide optimal child and family care ***(Allen and Vessey, 2004).***

Nurses need an in-depth knowledge of the theories of grief, loss, adaptation and change. In addition to the ability to understand and apply the underlying theoretical principles in the context of care provided to children with chronic illness and their families. Maintain an acute awareness of grief experienced by children and their family and how this affects their ability to adapt and adjust to the diagnosis. Nurses also need knowledge of child development to be able to recognize maladaptation or regression and put preventative or remedial strategies into place. It is also important that they accept the different coping patterns of parents and adapt the care they provide in response to individual need. Nurses are best placed to work with the chronically ill children admitted to hospital by developing close relationships with these children and their families. Nurses need to liaise closely with specialist team and share information to ensure that children and their families receive optimal care during hospitalization and after discharge home ***(Valentine and Lowes, 2007).***

Aim of the Study

Assess stressors and coping patterns of children suffering from chronic diseases and their mothers.

Research questions:

- What are the stressors facing both the chronically ill children and their mothers?
- What are the coping patterns of the chronically ill children and their mothers?
- Is there a relationship between the studied subject's characteristics and their coping patterns and the same for their mothers?

Chronic Diseases

Definition:

Chronic condition is any anatomic or physiologic impairment that interferes with the individual's ability to function fully in the environment ***(Lubkin and Larsen, 2006).*** Chronic illness is defined as a condition that interferes with daily functioning for more than 3 months in a year and causes hospitalization for more than one month in a year ***(Wilson et al., 2005)***. Chronic disease also defined as one which is generally characterized by uncertain cause, multiple risk factors and a long period of illness that does not improve without treatment and is rarely able to be cured ***(Boyd, 2004***). According to ***(Allen and Vessey, 2004)*** the chronic health condition was defined as one that at the time of diagnosis or during it's expected course will produce one or more of the following current or future long-term sequels: limitation of functions appropriate for age and development, disfigurement, dependency of condition, dependency on medical technology for functioning, need for medical care or related services that usual for the child's age and special ongoing treatments at home or in school.

A variety of definitions, several terms describe an illness or condition that is long-term and incurable and imposes limitations on the individual. Commonly used alternative labels in the literature include "children with special health care needs",

"impairment", "handicap" and disability ***(Wilson and Hokenberry, 2007).*** Children with special health care needs are children who have or are at an increased risk for a chronic physical, behavioral, developmental, or emotional condition and who also require health and related services of a type or amount beyond that required by children in general ***(McPherson et al., 2004).*** **Impairment** refers to physiologic or anatomic abnormalities or a loss or abnormality of structure or function. **Handicap** is a condition or barrier imposed by society, the environment, or one's own self and not a synonym for disability. Handicap describes the social consequences of the impairment resulting in an inability to attain satisfactory role fulfillment, especially the social response of others in the individual's environment. **Disability** is defined as a long-term reduction in the child's ability to engage in day-to-day activities (e.g., playing, attending school) because of a chronic condition ***(Michaud et al., 2004).***

Classification of a chronic health conditions:

According to ***Newackeck and Halfon (1998),*** the most common chronic childhood conditions causing disability are respiratory diseases (primarily asthma) and impairment of speech, sensory functions and intelligence (primarily mental retardation). Asthma is the single most prevalent cause of disability in children and has been largely responsible for much of the recent increase in childhood disability.

The chronic physical conditions are classified into the following categories **1)** selected skin and musculoskeletal conditions **2)** impairments (visual, hearing, speech, paralysis, deformity or orthopedic impairment) **3)** selected digestive conditions **4)** selected conditions of the genitourinary, nervous, endocrine, metabolic and blood forming systems **5)** selected circulatory conditions and **6)** selected respiratory conditions ***(Phipps and Monhan, 2003).*** While, ***Zendi (2005)*** classifies chronic illness as juvenile onset diabetes, muscular dystrophy, cystic fibrosis, rheumatoid arthritis, sickle cell anemia, seizure disorder, chronic renal disease, thalasseamia and hemophilia, leukemia and asthma. There are also small but increasing numbers of children who require procedures, such as tube feeding or bladder catheterilization.

The health providers especially nurses have a number of concepts to draw on to help them understand how families experience and respond to childhood chronic conditions. Uncertainty, stigma, normalization and survivorship are concepts that capture important aspects of many families' experiences ***(Allern and Vessey, 2004).***