

A PURPOSIVE STUDY ON IMPACT OF CHILDHOOD CHRONIC SICKNESS ON PARENTING AMONG PARENTS OF CHILDREN WITH CHRONIC DISEASE IN KAMALA NEHRU MEMORIAL HOSPITAL (KNMH), PRAYAGRAJ (U.P.)

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Abstract

A purposive and descriptive study was conducted on "Impact of Childhood Chronic Sickness on Parenting among Parents of Children with Chronic Disease in KNMH, Prayagraj (U.P.)". 30 samples explicitly children of age group 0-17 years were selected for the study. The whole purpose of the research was to study the treatment, consequences, problem met by child and family with coping tactics. The two questionnaire "A" & "B" were prepared to collect the required data for the study. Purposive sampling was used for study because the people had very specific features. The mean age of respondents was 8.65 ± 6.14 . Among the respondents 17 (56.6%) were male and 13 (43.3%) were female. Out of which 23 (76.6%) were working. Through this study we come to know the siblings were also affected, 25 (83.3%) of siblings positively and (04) 3.88% siblings negatively impacted, the kids of all the respondents were suffering from chronic illness.

Keywords: Purposive, Chronic Sickness, Parenting, Children

INTRODUCTION

Everyday thousands of kids suffer from the effects of chronic health condition and families struggles with ailment management and children's behavioural and emotional adjustment. Many parents experience difficulties with their care giving role and lack of confidence in their capability to manage their child's illness and ensure the child's wellbeing while their consistent evidence as to the extent and impact of childhood chronic illness. There is a possibility of guidelines and recommendation for the development of evidence-based parenting programmes for parents of children affected by chronic health conditions are provided. Relapsing back to the WHO's definition of health, chronic illness encompasses more than simply the physical disease, it also includes the effects on individuals and family's lives. Precisely, the occurrence of paediatric chronic illness has a deep impact on the well-being of parents, each family member, including healthy siblings. The burden of chronic illness in family produces stress in all aspects of life as:

***Financial**, in absence of insurance or the savings, piled up medical bills and household expenses are stressing;

***Physical**, the suffering child as well as the family member's normal routine gets disturbed;

***Emotional**, the stress and doubt about the future and upcoming procedure or extensive worrying about the sick child takes over the family's peace;

***Social**, the family either faces isolation and loneliness or get over burdened by extra attention, whether it be advices, opinions, judgements or blaming;

***Behavioural**, the family members are distracted and divided in different directions to fulfil different responsibilities as hospital visit or dropping/picking sibling from school, etc; Each and every member of the family from small to big is impacted in some way or the other by child's chronic illness.

OBJECTIVES

1. To find the impact of Childhood Chronic Disease on Child.
2. To determine the impact of Childhood Chronic Disease on Parents and others.
3. To identify the impact of Childhood Chronic Disease on family members and community.
4. To form guidelines for Coping strategies of stress from Chronic illness of Child, faced by Parents, Family members and Community.

HYPOTHESIS

H1: The chronic illness of child impacts positively on child, family members and community.

H2: The chronic illness of child impacts negatively on child, family members and community.

H3: The coping approaches could help decrease the severity of consequences and build up positive effect on child's and family's moral.

REVIEW OF LITERATURE

A group of people Alina Morawska, Rechal Calam, Jannifer Fraser presented a paper in Journal of Child Health Care (2015) on 'Parenting interventions for childhood chronic illness: A review and recommendations for intervention design and delivery' providing a narrative review of examining relationships between chronic childhood illness, emotional and behavioural disorders and parenting. Key guidelines and recommendations for the development of evidence – based parenting programs for parents of children affected by chronic health conditions are provided.

Other researchers group namely Maria Stella Epifanio, Vitalba Genna, Maria Grazia Vitello, Micelle Roccella, Sabina La Grutta from University of Palmer, Italy conducted a study (2013) on 'Parenting Stress and impact of illness in parents of Children with Coeliac Disease (CD)' which included 74 parents. The research result evaluates parent's perception of the CD impact and the parenting stress level, comparing 74 parents of both CD children and of healthy children.

One more researcher's pair of Karen Frankel & Marianne Z. Wamboldt (1998) evaluated 70 children/families at tertiary-care hospital for asthma. The most important predictors of how much impact a child's asthma has on the family are parental emotional distress and amount of social support. Analysis indicated that only the parent's Psychiatric Symptom Index significantly impact scores.

METHODOLOGY

To achieve the set objectives and to prove the hypothesis on the problem to accomplish the study, a simple purposive and descriptive study was conducted. Two set of Questionnaires "A" & "B" were prepared to collect demographic information and disease impact on child, siblings, family and community. Purposive sampling of 30 samples/parents of the children having chronic illness from the children's ward was done for this research study as the population had very specific attributes. All the respondents completed the survey completing & submitting the questionnaire.

RESULTS

The findings were analysed using inferential statistics. Through this study we tried finding the relation between different demographic domains impacted by child’s chronic illness. Some demographic data are proportionately related to stress level like low family income and age where the parents or care takers are immature or inexperience to go through such crisis conditions. The analysis was carried out on many demographic characteristics as age, sex, education, occupational status & income, comparison of ill & healthy child’s characteristics, positive & negative impact of illness on siblings & level of stress but only few of the relative data are presented on charts.

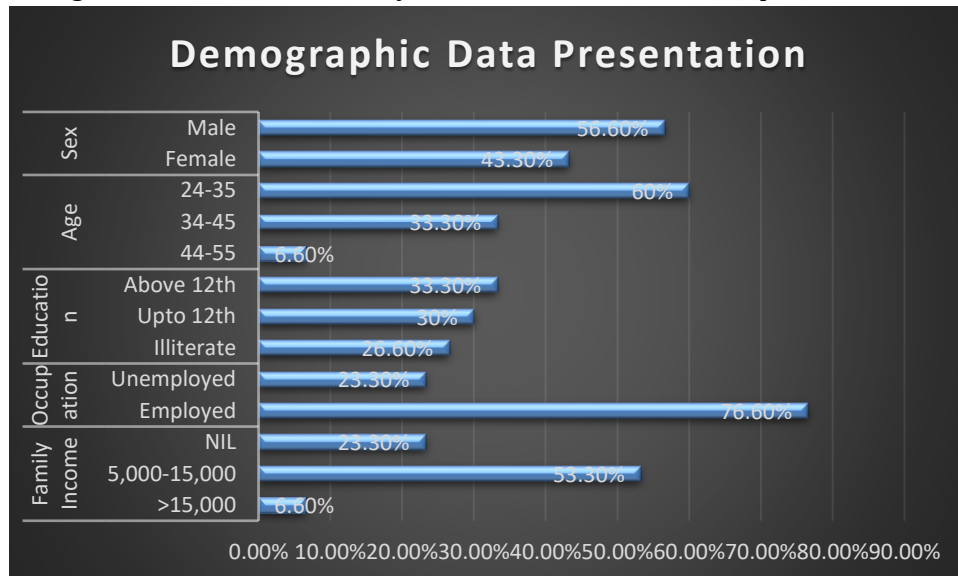


Fig 1: Demographic Characteristics of the suffering family members.

Findings revealed that the mean age of respondents were 8.65 ± 6.14 . The mean of level of stress scale is 39.33. Out of 30 suffering children family, 25 of the siblings i.e 93% of them are impacted, negative impact mean was 3.88 & positive impact mean was 4.32. In this study 12 (40%) respondents felt that their child’s illness impacted their siblings & 18 (60%) respondents felt that the siblings were not affected by their child’s illness.

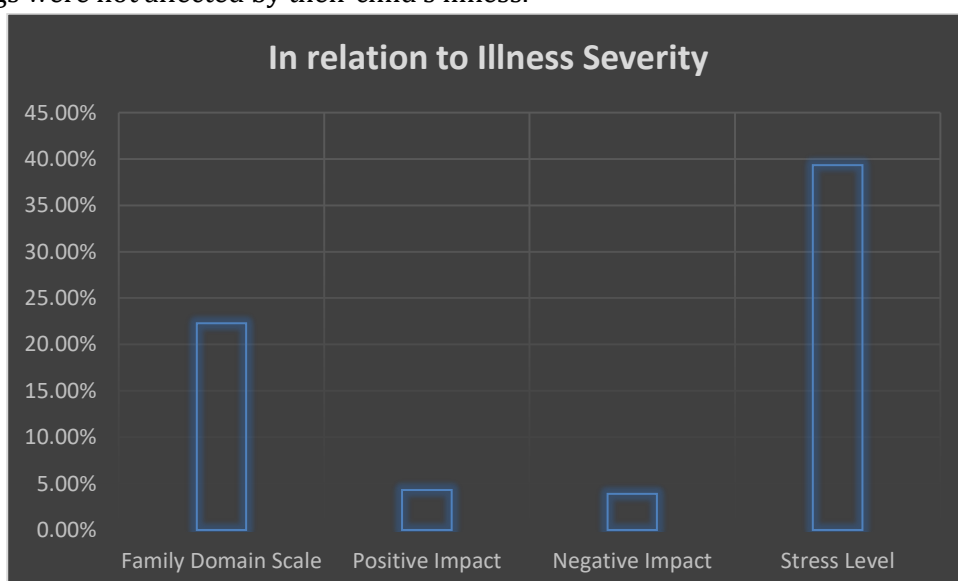


Fig 2: Impact of Illness severity on family domain.

NURSING IMPLICATIONS

- **Nursing practices:** Nursing personnel can serve as the liaison between the sick child, his/her parents and the community, to support each other emotionally, psychologically, physically, socially and if possible, financially.
- **Nursing Research:** It can direct researchers to find many possible ways to help people with options to cope up during such critical crisis period.
- **Nursing Education:** It can be added to the curriculum as a part of practice and research for both tutors and students as evidence – based practice.
- **Nursing Administration:** Can be applied in hospitals, to improve sick child's and his/her parents coping ability to face the crisis confidently and in colleges, to improve students' skill in maintaining inter-personal relationship with patients and parents

RECOMMENDATIONS

- A parallel study can be simulated/led using increased number of samples to generalize the findings.
- An adaptable plan can be developed based on need and finding of research study.
- A comparative study can be conducted in different hospital - care settings and findings can be compared.
- Follow up study can also be conducted to improve the coping mechanism strategy for different diseases.
- Follow up study can also be conducted to improve the coping mechanism for different needs of the child and the parents.

CONCLUSION

Consistent with previous studies, the results showed that parenting a child with any chronic illness takes toll on not only the kid but also on the sibling/s, parents, family members as well as community. The study concludes that there is a crucial need to formulate coping strategies or policies to support parents of suffering children get rid of their psychological, emotional, physical or financial stress in any ways possible.

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