Exploring Conceptual context for Resilience Assessment Scale for children with Renal Diseases.

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Abstract

The period of adolescence is considered as a developmental period that not only inculcates subjectivity to the life but also improves the critical thinking labelling environmental processes. Disease and sufferings are considered to be part of almost all age groups thus deteriorating physical and psychological well-being as a whole. Moreover, the course of hospitalization during the phase of disease can lead to stress, delayed coping mechanisms. The major factors that lead to the former are change in health shifts of the hospital staff, painful procedures, lack of social and peer engagements, separation from parents and most importantly loss of self-esteem. The process of hospitalization can lead to disturbed body image in the paediatric client, low self-esteem and confidence, delayed milestones and poor mental abilities in a long run. In order to combat the overwhelming physical and psychological conditions there is a need to develop a Resilience Scale that would help to identify the coping levels in the child and hence can help the health care professional ton provide efficient quality care. Towards systematic developmental process there is a need to formulate a conceptual model with the inter-related concepts or abstractions that would be assembled in a rational and explanatory scheme. The Conceptual framework is needed to be utilized through an extensive literature review supporting linkage of selected, interrelated concepts on the basis of Rosswurum and Larrabee Model that recognized the translation of research into practice. Resilience scale can further be developed through implementation of the conceptual; model that can help the health care professionals to provide psychological distractions and effective coping strategies before providing the physical treatments thus helping with an easy resilience.

Keywords: *Resilience, Resilience Assessment Scale, physical and psychological impairment, conceptual framework.*

Introduction

After the birth of the child, nutrition and adequate physiological processes leads to progressive development of various motor and cognitive skills. As the age progress with time development in a child takes place along with growth in physical, psychological, social and spiritual domains as a whole.[1] Development of a child leads to intellectual development along with physical development.(Chang & Kao, 2013).

Children during the period of growth and development go through various stages that inculcate their behaviour and response.[2] Around the age of 10-18 years, the theorists explained the overall development of the individual right from the childhood in aspects of cognitive development, psychosexual development, psychosocial development, moral development and development of faith respectively.(Yong & wong, 2009).

Children of age group 10-18 years engage themselves in school and learning. Their curiosity about the future goals and plans help them to attain a landmark of working within their capabilities (Lemos & Rodrigues, 2015). Majority of the children are strongly influenced by their friends, sharing the secrets and playing in smartest ways of inclusion of techno-advancements as well. [3,4]

Major reports and evidence for chronic diseases depict that most common chronic conditions among adolescents aged 10-18 years are asthma, diabetes, inflammatory bowel disease, renal diseases, sickle cell anaemia, hyperparathyroidism and obesity (Prasad N, 2015). Among all renal diseases are the most neglected

terms for the children of this age as symptoms for renal diseases again aggravate after once being supressed.[6]

Illness in the paediatric population can deteriorate the psychological ability, emotional well-being, spiritual stand and working capacity of the children as per the ages and hence slow down the developmental process.[7,8] Prolonged and frequent hospitalizations among the children with renal diseases offer them a stage that can affect the resilience and hence, the ability to nurture and outstand as per their age (Chen & Wang, 2016).[10,11]

Chronic kidney disease (CKD) is emerging to be an important chronic disease globally. Children from age groups 6-12 years of age usually suffers from various diseases among which, kidney failure is most common along with nephrotic syndrome presenting with ANASARCA, hyperlipidaemia and hypoalbuminemia.[12]

Various research evidence from the field of medical urology indicated that the repeated and prolonged hospitalizations among the children lead to disturbed physical and psychological abilities as well as the capability of the child to handle the obstacles also deteriorates(Wagnild & Young, 1993)[13]. The chronic renal diseases (acute glomerulonephritis, end stage renal disease, nephrotic syndrome) among the children aged 10-18 years leads to repeated hospitalizations and further relapse deteriorates the physical, psychological, social and spiritual domains. This leads to low resilience and hence low coping strategies among the children (Windle G, 2011)[14]

Lawrence. Erika et. al (2004) revealed that children with chronic renal diseases also feel difficult to Resile back because they personally feel guilty about the demands his or her illness makes on the family members.[15] Moreover, the presence of the chronic diseases among children leads to disturbed physical and psychological functioning due to change in patterns of daily living and series of hospital visits or admissions. Furthermore, the children with chronic diseases usually go through disturbed emotional and behavioural patterns thus affecting the coping strategies to illness. Also, situations of re-adaptations to current situation also lead to a negative impact on coping mechanisms. Quality of life gets disturbed not only among children but also among their families while dealing with chronic diseases.(Lin & Huang 2004).[16]

Children suffering from chronic diseases have higher levels of stress and low self-esteem due to prolonged hospitalizations and dependence on family for treatment and care.[17,18] The term "Resilience" came into the field of research way back to understand the concept of being competent despite of various adversities and prevailing psychological harm. Moreover, understanding Resilience among children becomes rather an essential part in an order to help the paediatric population to thrive from the situation of stress.(Lin & Huang 2004)

Resilience is taken as a major consideration for the current studies and thus adapting to find the useful measurement tools. Resilience in one domain does not confer resilience in other domains and related factors. Development of the Resilience Assessment Tool for the health care professionals following a conceptual framework and other methodological processes would help in assessing the psychological well-being along with disease management process.

Conceptual Framework Model for Resilience Tool: A Framework model is the connectivity of various concepts leading to development of a process thus explaining the relationship between all of them.[19,20] Conceptual framework helps a researcher to bring related observations and understand the dependence and independence with other related factors. The present study will aim to link various factors and concepts required to develop a Resilience assessment Scale according to "Rosswurum and Larrabee Model" thus translating the research evidences into actual practice. (Ozmay 2007).

Phases of Rosswurum and Larrabee Model:

Assess need for making Resilience Assessment Scale: Before undergoing of the developing task of the actual tool required for the children admitted with renal disease, extensive literature was reviewed regarding the available resilience scales for adults, adolescents and other related population. Review of literature had shown the variability and unavailability of the desired scales for the adolescents and child population in order to measure the concept of resilience during the course of the chronic illness. Moreover, very less number of resilience assessment scales has been developed for the adaptation and use in Indian settings particularly for the renal diseases. So, need of the development of resilience scale was assessed and further steps were inculcated in order to implement the plan of action.

1. **Link problem interventions & outcomes:** Thereafter, various standardized resilience tools

namely Wagnild and Young resilience scale, Brief resilience scale and Child and youth resiliency measure scale were reviewed and factors that build up resilience were reviewed and interlinked with the diseased condition. The previous literature for the available scales denoted various factors for Eg, Personal attributes, physical domain, psychological domain, social and intrapersonal domain that can help the adolescents gain resilience and this can further improve the outcome of the disease and course of hospitalization among the adolescent population.

2. **Synthesize best risk factors:** Various risk factors affecting the resilience process were identified by literature review and were listed which will help the investigator to further design and develop the factors for the study that can help the child to gain resilience during the journey of the illness. Various risk factors that can affect resilience are family functioning for promoting care and well-being, role of siblings in promoting the resilience, treatment course of hospitalization and nursing care that can lead to positive outcome and hence help the patient to achieve resilience and best possible outcome of health and well-being. Also, various developmental stages as per Piaget were considered that explained the areas of concern and developmental process as per concrete and formal operational stages for children aged 10-18 years.

3. **Design Resilience Assessment Scale:** The investigator identified various factors (**personal attributes, social domain and coping strategies adapted by the children with renal disease**) that affect resilience and render the ability to bounce back to state of adaptability and well-being. The factors together were incorporated in the form of single statements and preliminary draft was prepared. The first draft and subsequent drafts were rotated repeatedly among nine experts as a process of modified Delphi-technique.4 rounds of modified Delphi technique were carried out and modifications were made as per advised. The final draft of the resilience assessment scale was developed with total 31 items and maximum score was 155 and minimum was 31 with a cut-off score at 102.

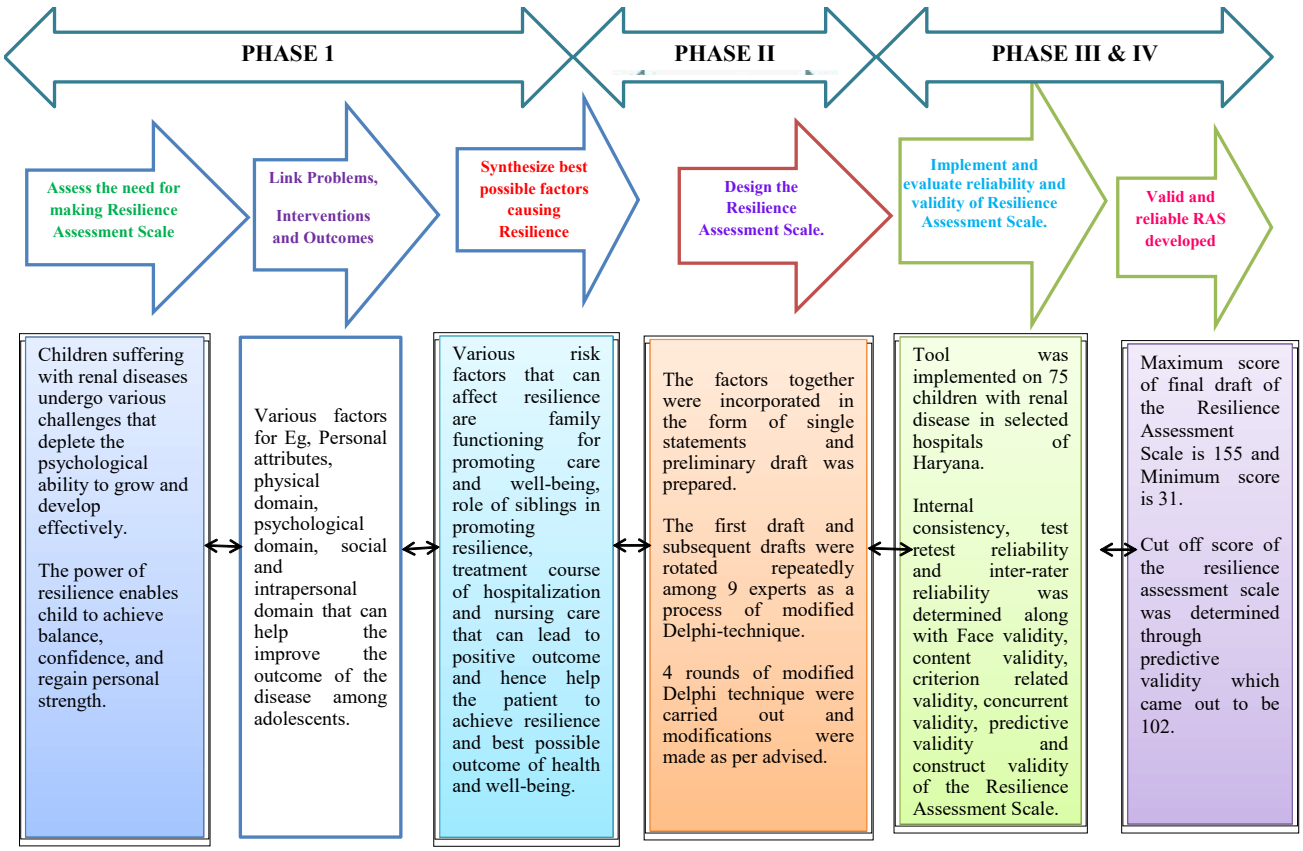

Figure 1: Rosswurm and Larrabee Model

4. **Implement & Evaluate the reliability and validity of Resilience Assessment Scale:** Tool was implemented on 75 children with renal disease in selected hospitals of Haryana. Internal consistency, test retest reliability and inter-rater reliability was determined along with not only Face validity, content validity, criterion related validity, but also concurrent validity, predictive validity and construct validity of the Resilience Assessment Scale.

5. **Valid and reliable Resilience Assessment Scale developed:** Modifications were made with total 56 items in the first draft to 31 items in final draft. The items were modified on basis of comprehension, adequacy in terms of understanding for the children and also to cover up their concentration capability up to set time period. Maximum score of final draft of the Resilience Assessment Scale is 155 and Minimum score is 31. Cut off score of the resilience assessment scale was determined through predictive validity which came out to be 0.7.

Implications:

Nursing Education:

- Resilience Assessment Scale can be included in teaching content of Renal Diseases for better understanding of the psychological impact of the diseased condition and its role in promoting resilience.
- Nurses can be educated to use the Resilience Assessment Scale while therapeutically treating the chronic disease as psychological consideration of the child is more important to understand while treating.
- Student nurses can be educated regarding understanding of the related domains/factors that affect the Resilience among children suffering from renal disease.
- Based on the future needs, the psychological trauma needs to be understood clearly before undergoing the diagnostic and therapeutic treatment regimen as a whole.

Nursing Practice:

- The tool can be used in different settings and outpatient departments to assess the level of Resilience among the children.
- Assessing the Resilience in chronic diseases will help the children to recover earlier in relation to psychological aspect and hence the child can be assessed for the capabilities to promote health in the journey of the disease condition.
- Nurses and Nursing students can use Resilience assessment scale for prediction of the renal patients for the level of the resilience achieved during the course of hospitalization and illness.

Nursing Administration:

- Resilience assessment scale can be made a mandatory tool for the pediatric patients to be filled during assessment during admission.
- The nursing administrators can make efforts to incorporate the use of the resilience assessment scale in assessing the level of resilience at time of readmission and subsequent discharge.
- The Nurse Administrators can make efforts to inculcate Resilience Assessment Scale in Pediatric wards and Intensive care units to assess for the resilience among the hospitalized children..

Further Recommendations:

- Studies can be conducted to establish factor analysis by undertaking large sample and other settings.
- Resilience scale can further be developed that can assess the resilience among children with all chronic diseases and also for their families in order to inculcate their point of views and issues that head them in caring for chronically ill child.
- Based on the present study, more factors which may influence resilience can be identified for further research.
- As per the present study, the resilience scale can be developed for the parents and primary care-givers to assess the resilience while caring up for their children with renal diseases or other diseases.
- Levels of the Resilience score can be interpreted as Low, Moderate and high by taking larger sample.
- Other age related phenomena's laid down by various theorists excluding Piaget's theory of growth and development can be undertaken and all developmental aspects can be undertaken as a future aspect.

Conclusion

Renal diseases among the children are the most common conditions that lead to prolonged and frequent

hospitalizations and thus, deteriorate the physical, psychological and social domain among the children (Simeone, 2009) .This in turn affects the learning and continuous interaction with the environment. The investigator in this instance developed the Resilience Assessment scale keeping in mind the need of understanding the psychological aspect of the child while other therapeutic treatment modalities. The Resilience Assessment scale mainly constituted various domains/ factors that affect the resilience among the children with renal diseases during the course of the illness. The Resilience Assessment scale consists 31 items including personal attributes, social domain, psychological domain and coping strategies opted by the child during the journey of chronic illness(Kimmel 2010).

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