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Methodological Study for RAS Development for Chronic Pediatric Population

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Abstract

Adolescence is considered as a difficult period filled with conflicts in search of self-autonomy, which culminates the rediscovery of an individual towards adult life introduction. In addition to being sick there are many other factors i.e. health care staff rotation, away from parents, experiencing pain during the procedures, peer detachment and loss of self-esteem during hospitalization. The objective of the study was to develop a scale for assessing resilience among children with Renal diseases. Methodological research approach was used for development of an effective Resilience Assessment Scale for children admitted with renal diseases. Study was done on 75 children aged 10-18 years admitted with renal disease in MMIMS&R Hospital, Mullana, Government Civil Hospital at Ambala and Kalpana Chawla Government Hospital at Karnal. The related review of literature ,experts guidance and investigator's personal experience, a list of factors/domains were identified and compared with standardized Resilience scales i.e., Wagnild and Young Resilience assessment scale, Child and Youth Resiliency measure. Modified Delphi technique was used for Content validation of Resilience assessment scale with 9 experts Content validity was ascertained by expert's opinion and was found to be 0.79.The range of rating score was 31-155 with the assumption that higher the scores, the greater the resilience. At a cut-off point of ≥102, the best balance between the sensitivity and specificity was achieved. Cronbach's alpha and inter item correlation were used to measure internal consistency of the tool, coefficient alpha was 0.81. Pearson correlation between resilience assessment scale and Wagnild Young resilience scale was 0.84. In order to estimate stability test re-test reliability was calculated and it came out to be 0.84.

***Keywords:** Resilience, Assessment scale, Children, Renal Disease*

Introduction

Background of the study

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.

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. Chronic kidney diseases are emerging to be an important aspect which needs close supervision in therapeutic as well as behavioural concept globally[1]. Stress was significant associated with risk of emotional and behavioural problems along with chronic diseases in adolescents interferes with adherence to treatment regimens and alters the psychological functioning. By the decade of the 1990's, researchers became increasingly focused on a phenomenon known as resilience. Resilience is the ability of the individual to bounce back from difficult experiences.[2-3]

This psychological abilities and positive attitude among children goes on deteriorating when the child goes through the pathway of chronic treatment. Coping during this(chronic) period and identifying the coping has become a major concern which is termed as "Resilience". Resilience is the word derived from "Resile" [4]which

means to "bounce or spring back"(re-"back"+ salire-"to jump, leap;) . Resilience is a resistance to be sick, adopted, thrive and ability to leave the state of illness by recovering out of it. [5]

Need Of The Study

Measures that have been developed to assess "resilience" have focused the factors and resources that make them possible to achieve.[6]

Adolescents and youngsters who confront chronic illness, usually experience a wide variety of stressors that can pose the threat of producing psychological disorders. There is a need for chronically ill child to alleviate the symptoms , which needs physical and lifestyle modifications, besides its affects the routine activities of child too like sports and school. One of the reason can be regular ongoing treatment of the child. These factors confine the chances of regularity and, produce hurdles in social relationships and create positive concerns about the future.

It is necessary to regain the lost activity, positive perception and functional outlooks and above all educational strengths and behavioural ratings among the children suffering from the renal diseases. Very few studies and literatures have reported to the development of tool to measure resilience and other related resources specifically for the renal diseases in paediatric population. Children with chronic diseases undergo various health challenges such as inability to maintain nutritional balance, metabolic defects, physical and mental challenges. These challenges further pose a serious disability threat among children to follow their developmental deprivations and for their families to render those children the desired cooperation.

So in this instance resilience assessment scale was designed up for the children aged 10-18 years suffering from chronic diseases in order to rule out the extent of the resilience acquired in relation to social domain, personal attributes, physical domain, psychological domain and also to gather various coping strategies used by the child to regain back the maximum potential for health and well-being. Nurses besides therapeutic regimen should also understand the psychological need and mental abilities of the child hospitalized with chronic disease in order to render quality and effective care and thus promote rehabilitation and resilience.[7]

Methodology

Methodological research was conducted on 100 children aged beyond 10 years for upto 18 years with chronic diseases in Paediatric wards and Intensive care units of Mullana, Government Civil Hospital at Ambala and Kalpana Chawla Government Hospital at Karnal.

Assent form was created in Hindi language and the consent was obtained from parents, which confirm the willingness of participants to be a part of this study. The aim of research study was explained to the subjects and confidentiality of the study subjects was ensured.

1. Phases of the Study

Phase 1: Preliminary Preparation

1) Review of literature

Extensive ROL was studied and the factors/domains affecting resilience were selected for the preparation of preliminary preparation of first draft.

2) Item pool generation

An exhaustive list of the factors which plays an important role in attaining resilience among children with chronic diseases was prepared from literature review.

3) Preparation of Preliminary Draft

The blue print of resilience assessment scale for children with chronic disease was prepared. Suggestions from the children and their parents suffering with chronic diseases followed by qualitative analysis from the same helped to rule out their concerns in the diseases conditions and strategies to cope up with their diseased condition.

Phase 2: Validation of first draft and subsequent drafts.

Validation of resilience assessment scale was done by four rounds of modified Delphi technique. Drafts were given to seven experts from the field of paediatric nursing and paediatric medicine and their suggestions were incorporated for the preparation of subsequent drafts. Modifications were made as per their suggestions

and content validation and content validity index of the final draft of resilience assessment scale was calculated. The final draft of the resilience assessment scale contained 29 items related to Personal Attributes , Social Domain , Psychological Domain and Coping Strategies opted by the child during the journey of chronic illness. The scoring criteria for resilience is as under:

S. No.	Levels	Range of Scores
1.	High Resilience	107-145
2.	Moderate Resilience	68-106
3.	Low Resilience	29-67

Phase 3: Pilot study

The Resilience Assessment Scale was administered to 10 children with chronic diseases from MMIMS&R hospital, Mullana after finalization of the second draft. The items were converted to Hindi and given to the children as self-administered questionnaire. The result of the pilot study after first administration indicated that the language of items was clear but somewhere misinterpreted by the children. The investigator has to restate and re-comprehend the sentence for its easy understand ability for the child. The average time taken for responding to the components of the Resilience Assessment Scale from one patient was 30-40 minutes .So, in subsequent drafts, structured interview was opted that was comfortable for the patient as well as for the investigator.

Phase 4: Final try out of Resilience Assessment Scale

Resilience assessment scale was translated to Hindi for understanding of the child. Data was collected from patients with chronic diseases after translating the Resilience Assessment Scale from English to Hindi and further from Hindi to English for sentence Re-verification. The scale was administered to 100 children suffering with chronic diseases in the month of August to October 2015. The average time taken in completing the Resilience Assessment Scale from one patient was 40-45 minutes.

Scoring criteria was modified for easy understanding for the child and further 5 coloured pens were used for Likert scale interpretation such as:-

5=All of the time (>8 times/ 10 times)

4= Most of the time (6-8 times/10 times)

3=some of the time (4-6 times/10 times)

2= A little of the time (2-4 times/10 times)

1=None of the time (<2 times)

RELIABILITY

a) Internal consistency

Data was analysed by using SPSS (version 21.0) .To ensure the internal consistency, reliability of measurement scale; the Cronbach's alpha was used. The scale was consist of 29 items and the overall calculated Cronbach's alpha coefficient was 0.81. (Cronbach's alpha coefficient should be >0.70).[8]The resilience assessment scale for the patients suffering with chronic diseases was found to be highly reliable in terms of assessing the child's ability to spring back to previous state of well being.

Table 1 Reliability analysis of resilience assessment scale, by using Cronbach Alpha

S.NO	Items	Corrected Item–total correlation	Cronbach's alpha if item deleted
1. O	I like to play with my friends whenever I feel.	.432	.805
2.	I report any unusual sign or symptom to my parents.	.458	.803
3.	I take my favorite story books, games along with me during hospitalization.	.342	.808
4.	I like to watch T.V, play video games, mobile handling during my free time.	.414	.802
5.	I like to play outdoor games like badminton, boll dosing, going a new place to a market, fun park, water park etc. with siblings and neighbors.	.439	.813
6.	I discuss my personal problems with my teachers (disease related).	.326	.805
7.	I try to compensate my absenteeism by studying extra hours and with help of my class mates.	.455	.805
8.	I take help of my teachers in completing my homework and assignments.	.551	.796
9.	I like to take part in co-curricular activities (school games, drawing competitions, and art and craft workouts.)	.422	.802
10.	I like to do my daily care activities myself.	.344	.805
11.	I feel hard to snap back when something bad happens (sensitive to situations).	.225	.809
12.	I have a mentor with whom I share my worries and feelings.	.374	.814
13.	I know that I would get well as early as I take my all medication on time. .	.451	.800
14.	I go for regular follow up as and when advised.	.421	.817
15.	I feel confident with parent's presence during hospitalization.	.546	.796
16.	I sleep for 8-10 hours daily.	.568	.796
17.	I feel confident with parent's presence during hospitalization.	-.039	.801
18.	My past record in school gives confidence for newer achievements and challenges.	.478	.800
19.	I try to see the positive side of the happening situation.	.450	.802
20.	I believe that there stands a supernatural power that holds me safe during my illness.	.629	.798
21.	I do meditation daily.	.060	.813
22.	I like to be with myself as and when troubles face me.	.319	.806
23.	I learn from my mistakes.	.318	.806
24.	I come up with different ways to handle a tough situation.	.418	.802
25.	My parents feel pride for my achievements.	.069	.814

Cont... **Table 1 Reliability analysis of resilience assessment scale, by using Cronbach Alpha**

26.	I try to work hard more in a situation when my teacher expects best out of me for my school work.	.451	.801
27.	My family helps me whenever I need them.	.032	.814
28.	I try to work out problems by talking or writing about them.	.360	.808
29.	I think myself as a strong person to deal with difficulties.	.329	.806

b) Equivalence of resilience assessment scale:

Inter-Rater Reliability

Inter Rater reliability calculated with Cohen's Kappa and it was found to be 0.76 for the resilience assessment scale for the children suffering from chronic diseases.

c) Stability of resilience assessment scale:

Test Retest Reliability

During the final try out of the resilience assessment scale, the test retest group was formed from 10 patients suffering with chronic diseases. The tool was coded with order number 1 to 10.The patients were interviewed with Resilience Assessment Scale. After 5 days, same patients were interviewed with same code number. Karl Pearson test was applied. The total instrument test retest reliability was 0.80.(normal value of Test Retest reliability is .70-1).[8]

Validity

a) Content validity

The content validity index was calculated and the Performa was circulated to experts .The CVI was 0.71 (If the values CVI is > 0.78, it shows good content validity)

b) Concurrent validity:

Wagnild and Young Resilience scale (Variable 1) was used as a Gold Standard because the items in the scale are similar to the items in the Resilience Assessment Scale (Variable 2) and the scale was also used for the adolescents. Pearson correlation between the resilience assessment scale and Wagnild and Young resilience scale, was calculated for concurrent validity.

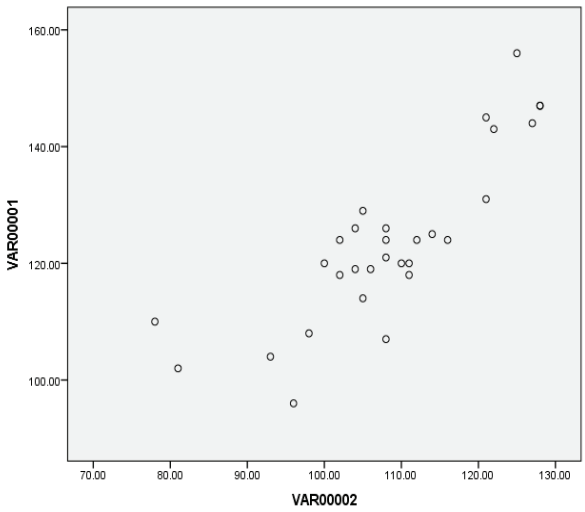

Figure 1: Positive correlation showing relationship between Wagnild and Young resilience scale and Resilience Assessment Scale for children suffering with chronic diseases. .

Table 2 Methodological analysis

Cut of Point Total Score	Sensitivity %	Specificity %	Ppv %	Npv %
>=59	100	0	70	-
>78	100	11.11	72.4	100
>81	100	22.22	75	100
>93	100	33.33	77.8	100
>96	100	44.44	80.8	100
>98	100	55.56	84	100
>100	95.24	55.56	83.3	83.3
*>102	100	100	86.4	75
>104	80.95	66.67	85	60
>105	76.19	77.78	88.9	58.3
>106	71.43	77.78	88.2	53.8
>108	57.14	88.89	92.3	47.1
>110	52.38	88.89	91.7	44.4
>111	47.62	100	100	45
>112	42.86	100	100	42.9
>114	38.1	100	100	40.9
>116	33.33	100	100	39.1
>121	23.81	100	100	36
>122	19.05	100	100	34.6
>125	14.29	100	100	33.3
>127	9.52	100	100	32.1
>128	0	100	-	30

c) Construct Validity :

Factor analysis

Exploratory factor analysis was used in identifying the key factors of resilience assessment scale. The value for Kaiser –Meyer Olkin (KMO) and Bartlett's test of sphericity was applied to assess the tool for its eligibility for carrying out factor analysis statistically. The value for Kaiser –Meyer olkin was <.60 and whereas p value of Bartlett's test of Sphericity was >0.05, which was not significant. It shows that the data was not appropriate for factor analysis.so, factor analysis findings were not considered.

Discussion

The Resilience Assessment scale constituted various domains/factors that affect the resilience among the children with chronic diseases during the course of the illness. The Resilience Assessment scale consisted 29 items including personal attributes , social domain , psychological domain and coping strategies opted by the child during the journey of chronic illness. Child and youth resiliency measure, CYRM was developed for the adolescents which included personal attributes, community domain, peer domain and contextual connectedness.

Wagnild and Young developed a 25 item Resilience Scale, RS for the adolescent children to check for the resilience achieved in overall domains including personal competence and acceptance of self and life.

Also, Resiliency tool was developed for chronic diseases. The questionnaire was divided into three domains interpersonal characteristics, characteristics of coping, and intrapersonal characteristics. Factor analysis has shown five factors; positive self-understanding, self-reliance, resourcefulness, perception of positive family relationships, and intimacy.

Investigator calculated internal consistency of resilience assessment scale and found it to be highly reliable that is 0.81.Similarly, Wagnild and Young developed a resilience scale and similarly calculated internal consistency and was also found to be reliable that is 0.91.

A study conducted on development of tool calculated the concurrent validity by correlating with other resilience measures and found it to have positive correlation. Also,

The correlation of Resilience assessment scale was found to be highly correlated with another measure that is Resilience scale.

Conclusion

The study was concluded with the help of findings that the resilience assessment scale consists of total 29 items including personal attributes , social domain , psychological domain and coping strategies opted by the child during the journey of chronic illness.

The resilience assessment scale developed by the investigator is valid and reliable and can be used effectively to predict the patients for resilience in chronic diseases.

Ethical Clearance: An ethical clearance was granted by the research and ethical committee of M.M College of Nursing, M.M University, Mullana, Ambala.

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Conflict of Interest : Researcher hadn't any conflict of interest

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