

# Development of Resilience Assessment Scale for Children Admitted with Renal Disease

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**Abstract:** Adolescence is considered a difficult period, marked by conflicts in search of one's autonomy, which culminates with the redefinition of the individual towards adult life introduction. Besides being sick there are related factors such as changing health care team shifts, pain due to various rendering procedures, parental separation, peer detachment and loss of self-esteem during the course of 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. From 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  $\geq 102$ , 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 calculated in order to estimate concurrent validity and it came out to be 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

## 1. Introduction

### 1.1 Background of the Study

Growth is the progressive increase in the size of a child. Development is progressive acquisition of various skills (abilities) such as head support, speaking, learning, expressing the feelings and relating with other people. 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. Child development refers to how a child becomes able to do more complex things as they get older. Growth and development goes side by side such that as growth of the child take place Intellectual.<sup>1</sup>

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 disease (CKD) is emerging to be an important chronic disease globally. From birth to age 4, birth defects and hereditary diseases are the leading causes of kidney failure. Between ages 5 and 14, kidney failure is most commonly caused by hereditary diseases, nephrotic syndrome, and systemic diseases. Between ages 15 and 19, diseases that affect the glomeruli are the leading cause of kidney failure, and hereditary diseases become less common.<sup>2</sup> The pretending facts in accordance with renal diseases include albuminuria, hyperlipidaemia, ANASARCA and hypalbuminemia.<sup>3</sup>

By the decade of the 1990s, researchers became increasingly focused on a phenomenon known as resilience. Resilience has been defined as the ability to remain competent despite unrelenting adversities, and it also refers to the ability to bounce back from or rebound from psychological harm.

Besides being sick there are related factors such as changing health care team shifts, pain due to various rendering procedures, parental separation, peer detachment and loss of self-esteem during the course of hospitalization. This attitude among children goes on deteriorating when the child goes through the pathway of chronic cure. Coping during this period and identifying the coping has become a major concern which is termed as "Resilience". Resilience is the word derived from "Resile" <sup>4</sup> which means to "bounce or spring back" (re-"back"+salire-"to jump, leap;"). Resilience is defined as resistance to illness, adaptation and thriving, the ability to bounce back or recover from stress.<sup>5</sup>

## 2. Need of the Study

During the past decade, resilience has increasingly become a focus of research in the behavioural and medical sciences. Measures that have been developed to assess "resilience" have not focused on these qualities but on the factors and resources that make them possible.<sup>6</sup>

Children and young people who live with a chronic illness experience a range of persistent stressors that can increase their risk of developing mental health problems. Chronically

ill child may need to manage symptoms that introduce physical and lifestyle limitations, including restricted participation in school and sport, as well as treatment effects and the impact of incorporating ongoing treatment into daily activities. These factors may limit spontaneity, create challenges for social relationships, and generate concerns about the future.

It is necessary to regain the lost activity, positive perception and outlooks and above all educational strengths and behavioral ratings among the children suffering from the renal diseases. Very few studies and literatures have reported to development of tool to measure resilience and other related resources specifically for the renal diseases in pediatric population. Also the children with renal diseases undergo various health as well as wellness challenges such as nutritional workouts, metabolic defects, physical and mental challenges as well. These challenges further pose a serious disability among children to follow and families to render them cooperation.

So in this instance resilience assessment scale was designed up for the children aged 10-18 years suffering from chronic renal 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 ability of the child in order to render quality and effective care and thus promote rehabilitation and resilience to the sick child.<sup>7</sup>

### 3. Objective

To develop a scale for assessing resilience among children with Renal disease

### 4. Methodology

A methodological approach was used for the development of resilience assessment scale for the children admitted with renal disease. The study was conducted on 75 children aged 10-18 years with renal disease in Paediatric wards and Intensive care units of MMIMS&R Hospital, Mullana, Government Civil Hospital at Ambala and Kalpana Chawla Government Hospital at Karnal.

Ethical approval to conduct study was obtained from institutional ethical committee of M.M University, Mullana. Assent form was prepared in Hindi and the consent was taken from the parents of the study subjects regarding their willingness to participate in the research project. The purpose for carrying out research project was explained to the subjects and assurance of confidentiality was given.

### 5. Phases of the Study

#### Phase 1: Preliminary Preparation

This phase was completed in three steps:

#### 1) Review of literature

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

#### 2) Generation of item pool

An exhaustive list of the factors which plays an important role in attaining resilience among children with renal diseases was prepared from literature review. Related factors contributing to Resilience such as personal attributes, physical domain, social domain, health related outcomes and various coping strategies used up by the child etc., were selected from the content and the items were pooled together.

#### 3) Preparation of Preliminary Draft

The blue print of resilience assessment scale for children with renal disease was prepared. Suggestions from the advisor and co-advisor followed by qualitative analysis from the children suffering from renal disease and their parents 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 nine experts and their suggestions were incorporated for the 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 31 items related to Personal Attributes, Social Domain, Psychological Domain and Coping Strategies opted by the child during the journey of chronic illness. The range of rating score was 31 to 155, with the assumption that higher the scores, the greater the resilience.

#### Phase 3: Pilot study

The Resilience Assessment Scale was administered to 10 children with renal diseases from MMIMS&R hospital, Mullana after finalization of the second draft. Firstly, in 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 understandability 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.

Scoring in the drafts was done on the basis of 3 coloured pens for the easy understanding for the patient. Scoring was done as:-

**Green:** Many of times

**Blue:** Sometimes

**Red:** Never

#### 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 renal patients 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 75 renal children in the month of February to April 2015. The average time taken in completing the Resilience Assessment Scale from one patient was 30-40 minutes. Scoring criteria was modified for easy understanding for the child and further 5 coloured pens were used for Likert scale interpretation such as:-

**{Green}** 5=All of the time (>8 times/ 10 times)

**{Yellow}** 4= Most of the time (6-8 times/10 times)

**{Blue}** 3=Some of the time (4-6 times/10 times)

**{Black}** 2= A little of the time (2-4 times/10 times)

**{Red}** 1=None of the time (<2 times)

#### Reliability

##### a) Internal consistency

Data was analysed by using SPSS (version 20.0). To find out internal consistency, reliability of present scale; the Cronbach's alpha was used. There were total 31 items in the scale and overall Cronbach's alpha coefficient of present scale was 0.81. (Cronbach's alpha coefficient should be >0.70).<sup>8</sup>

**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	I like to play with my friends whenever I feel.	.332	.805
2	I report any unusual sign or symptom (body puffiness, pain, decreased urine output, thirst, headache, shortness of breath, weight changes) to my parents.	.398	.803
3	I take my favourite story books, games along with me during hospitalization.	.282	.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, ball tossing, going a new place to a market, fun park, water park etc. with siblings and neighbors.	.149	.813
6	I discuss my personal problems with my teachers (disease related).	.326	.805
7	I try to compensate my absenteeism by working extra hours and with help of my class mates.	.355	.805
8	My teachers help me out in completing my work.	.551	.796
9	I render cooperation from my teachers when I am unable to learn effectively (during illness.)	.422	.802
10	I like to take part in co-curricular activities (school games, drawing competitions, and art and craft workouts.)	.344	.805
11	I like to do my daily care activities myself.	.225	.809
12	I feel hard to snap back when something bad happens (sensitive to situations).	.074	.814
13	I have a mentor with whom I share my worries and feelings.	.451	.800
14	I am frustrated on times when ceased from eating my favorite dish (E.g.: Spicy food, oily food.).	.121	.817
15	I know that I would get well as early as I take my all medication on time.	.546	.796
16	I go for regular follow up as and when advised.	.568	.796
17	I feel confident with parent's presence during hospitalization.	-.039	.801
18	I sleep for 8-10 hours daily.	.478	.800
19	I like to study effectively as per my capacity of doing efficient work.	.450	.802
20	My past record in school gives confidence for newer achievements and challenges.	.629	.798
21	I try to see the positive side of the happening situation.	.060	.813
22	I believe that there stands a supernatural power that holds me safe during my illness.	.319	.806
23	I pray whenever in trouble and meditate daily.	.318	.806
24	I like to be with myself as and when troubles face me.	.418	.802
25	I learn from my mistakes.	.069	.814
26	I come up with different ways to handle a tough situation.	.451	.801
27	My parents feel pride for my achievements.	.032	.814
28	I try to work hard more in a situation when my teacher expects best out of me for my school work.	.260	.808
29	My family helps me whenever I need them.	.329	.806
30	I try to work out problems by talking or writing about them.	.347	.804
31	I think myself as a strong person to deal with difficulties.	.268	.807

Corrected item to total correlation was applied on 31 items of the scale, 24 items in the scale had item score to total score correlation between 0.2-0.7 whereas 7 items in the scale had item score to total score correlation less than 0.2 showing in compatibility with the overall tool but the items in the tool were not deleted as the reliability coefficient was constant or less than 0.81.

##### b) Equivalence of resilience assessment scale:

###### Inter-Rater Reliability

Inter Rater reliability was calculated on 10 patients by Cohen's kappa and was found to be 0.74 for the resilience assessment scale

##### 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 15 patients with renal diseases. The tool was coded with order number 1 to 15. 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 0.84.(normal value of Test Retest reliability is .70-1).<sup>8</sup>

### Validity

#### a) Face Validity

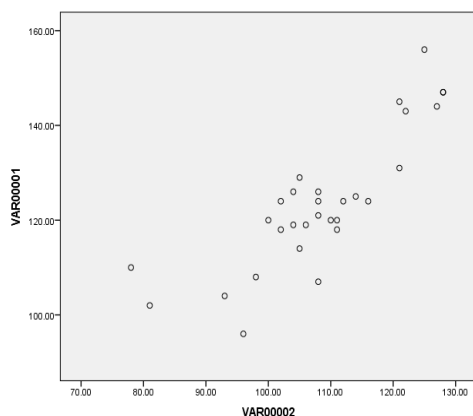
The practical tool in the assessment of face validity is an expert panel; by seeing the tool majority of experts suggested that all the domains contributing in promotion of resilience are well organized and structured. Thus, the face validity of the tool was considered good.

#### b) Content validity

Content validity Performa was circulated to the panel of experts which was having 31 items and experts were asked to evaluate the items. Content validity of resilience assessment scale was checked by calculating the content validity index (CVI) through the Performa filled by the experts. Content validity index came out to be 0.79 (values of CVI higher than 0.78 are considered having good content validity)

#### c) 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. Data was calculated from 75 patients with the help of both the tools. The value of Pearson correlation came out to be 0.84; signifying that there was positive correlation between both the tools.



**Figure 1:** Positive correlation showing relationship between Wagnild and Young resilience scale and Resilience Assessment Scale

#### d) Predictive Validity

It reveals Sensitivity, Specificity, Positive Predictive Value (PPV), Negative Predictive Value (NPV) tests of the Resilience Assessment Scale, RAS for prediction of resilience among children with renal diseases, and these were calculated at each score from 78 to 128. sensitivity was ranging from 0 to 100%. At a cut-off point of >102, the best balance between the sensitivity and specificity was achieved, i.e. Sensitivity was 90.48 % ,Specificity was 66.67

%,Positive Predictive Value was 86.4% and Negative Predictive Value was 75%. Since cut –off point of the tool was 102, patients who are having a score  $\geq 102$ , are at level of achieving Resilience in renal diseases.

**Table 2:** Sensitivity, Specificity, Positive Predictive Value (PPV), Negative Predictive Value (NPV) Tests

Cut Off Point Total Score	Sensitivity %	Specificity %	PPV %	NPV %
$\geq 78$	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
$\geq 102$ *	90.48	66.67	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

#### e) 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 means that the data was not suitable for factor analysis. So, factor analysis findings were not considered in the resilience assessment scale.

## 6. Discussion

The investigator 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. 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. Components of the questionnaire were in 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 the 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.

## 7. Conclusion

The conclusion was drawn from the findings of the study that the resilience assessment scale consists of 31 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 renal diseases.

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