DEVELOPMENT AND VALIDATION OF A SCALE TO MEASURE SOCIAL SUPPORT AMONG INFORMAL CAREGIVERS OF CHILDREN WITH INTELLECTUAL DISABILITY.

ALIU, D.A[1], OSINOWO, H.O[2] and ISHOLA, A.A[2],
[1]*Irebamibo Pearl Centre of Hope, Lagos, Nigeria*
[2]*Department of Psychology, Faculty of Social Sciences,*
University of Ibadan, Nigeria

ABSTRACT

Social support has long been regarded to mitigate distress and considerable research has been directed at its role in parents caring for a child with intellectual disabilities. Beyond the assessment of sources and quality of social support, this study included perceived cognitive assessment of these support received. We conducted a qualitative study to determine perception of the nature and type social support received. Themes were generated, and those related to sources, nature and assessment of social support were used in constructing a 9-item Cerebral Palsy Social Support Scale (CPSSS). A descriptive cross-sectional survey was then conducted among 150 mothers of children with Cerebral Palsy, aged 25-60, in a Clinical settings of Tertiary hospitals in South Western Nigeria to assess the reliability and validity of the scale. Construct validity using exploratory factor analysis factored and Varimax rotated the scale into three dimensions (KMO = .61, X^2 = 428.42, df = 36, p<.001) with items loading ranged from 0.68 to .98. Internal Construct validity shows that the three dimensions correlated with CPSSS overall scores. Two of the three subscales (Emotional/Informational support, Financial/Moral Support) were sufficiently related while façade (Stigmatized) support was non-correlate of other components Convergent validity was established between CPSSS and Multidimensional Perceived Social Scale (r = .45, p<.001). The overall CPSSS (α =.88) and its sub scales demonstrated meritorious reliabilities (Emotional/Informational support, α =.90, Financial/Moral Support, α =.72; façade (Stigmatized) support, α =.89). The brief Cerebral Palsy Social Support Scale was a reliable and valid means of assessing the nature of social support received by Cerebral Palsy caregiver in Nigeria.

Keywords: *Cerebral Palsy: Social Support; Emotional/Informational, Financial/Moral, façade (Stigmatized) support*

INTRODUCTION

Social support is the perception or actualization of care or assistance from a social network. It can be emotional, tangible, informational, or companionship that is either subjectively perceived or objectively received (Taylor, 2011). Social support has long been regarded to mitigate distress and considerable research has been directed at its role in parents caring for a child with intellectual disabilities. It has generally been found to minimize the impact of caregiving and that those parents with greater social support show better psychological adjustment (Ozbay, Johnson, Dimoulas, & Morgan, 2007). Social support has other important functions in that, carers may find out about services from people who have used them before and form a network. The literature discusses several types of social support, both formal and informal. Schopler and Mesibov (1984) define formal social support as the assistance that is social, psychological, physical, or financial and is provided either for free or in exchange for a fee through an organized group or agency, while defining informal support as a network that may include the immediate and extended family, friends, neighbours and other parents of children with disabilities.

Social support affects health by protecting people against the negative effects of high stress (Sarafino, 2002). It has an effect upon an individual's psychological wellbeing during stressful life events. Social support works by making people with higher levels of social support appraise situations as less stressful and also by modifying people's responses to a stressor after initial appraisal such as somebody providing them with a solution to their problem. This means events are stressful in so far as people have negative thought about the event (Gruetzner, 2001).

Cultural variations have been found in the nature and dynamics of social relationships, including certain values regarding the interconnectedness of individuals within families and other important social group structures, as well as attitudes regarding seeking assistance from more formal support systems (Thompson, 2015). Others have asserted that such variations in social support are multidimensional and extend beyond basic categories of race/ethnicity to also include key dimensions of language proficiency, language preference, level of acculturation, ethnic density in community, among others (Mulvaney-Day, Alegria & Sribney, 2007; Turney & Kao, 2009).

The current development of social support measures was conducted to create a measure of social support, particularly those which include nature and types of social supports received from the significant others in the environment. Beyond the assessment of sources and quality of social support, this study included faked social support or received from families and friends. This kind of social support is often delivered as non- empathetic social support i.e expressing concerns and showing prejudice at the same time. Parents of special needs children may experience a variety of stigma, ranging from actual biases based on their condition (“enacted stigma”) to perceptions of stigma that may not actually exist (“felt stigma”). Parent also experience “courtesy stigma”—the stigma of affiliation that applies to people who associate with stigmatized groups rather than through any quality of their own (Goffman, 1963). This stigma has valence content which is beliefs and experiences related to the knowledge and attitude towards cerebral palsy. For instance, people in Nigeria cultures often stigmatized parents of mentally and physically challenged as victims of spiritual attack, parents of evil children or witches, they offer support if requested to the parents but refuse to have any form of physical contact or involvement in order not be attacked spiritually or become victims themselves. These beliefs and experiences are considered valence because they make the person feel better or worse about the self. For example, some people may feel ashamed or embarrassed about how people express support to them, whereas others do not. The nature of this kind support undermines the person wellbeing instead of improving it. For example, Hudson et. al (2009) found that barriers to treatment among homeless youth were non-empathetic social support received from mental health providers. This study builds on Mickelson’s studies and revisit social support questions in a context where stigmatization and cultural support was evaluated (Nielsen, 2009).

METHODS

Item Generation

In developing the cerebral palsy social support scale, a self-administered, was developed using a combined qualitative–quantitative approach. The researcher conducted a qualitative study in form of Focus Group Discussion with mothers of children living with Cerebral palsy.

The interviews were recorded, translated and transcribed. From thematic analysis of the FGD, two themes emerged after analysis of various responses. Social needs, such as emotional, financial and informational support in other to restructure and readapt their social life which have been disrupted in families having such child as a result of perceived non acceptability of the child due to inconveniences or unavailability of assistive facilities necessary for the child. It was expressed that it is expensive taking care of a child living with cerebral palsy. They expressed that cerebral palsy children have quite a lot of assistive facilities needed for support which are expensive and may become useless as the child outgrows it, thereby making the caregivers spend more. The second theme revolved round the stigmatisation. Stigma and inadequate social services and lack of support from government and public were emphasized. A critical aspect is the pretended support the caregivers abhor. Yet many of them have to contend with societal pretentions that affects their psychological wellbeing.

Face Validity

From the themes, the researcher generated 14 items. The items were presented to 10 experts, made up of clinical psychologists, psychiatrist, nurses and social workers, to rate the appropriateness of each items to establish the content validity (Nunnally, 1978).

They were also asked to assess the items with a view to determine if the questionnaire contained relevant items for assessing social support in the Nigerian context. The items were judged as appropriate by 8 out of the 10 experts that the questions measured social support from the context of informal caregiver of children with intellectual disability. The 14 items were then made into questionnaire format using Likert style scale ranging from 7=Very Strongly Agree, 6= strongly agree, 5= Mildly agree, 4= Neutral; 3= Mildly disagree, 2= Strongly disagree to 1= Very Strongly disagree.

Ethical considerations

After getting institutional approvals, ethical permission was granted by the ethical review board of the Federal Neuro Psychiatric Hospital Lagos. Written consent was requested from consenting caregivers for participation in the study. This was done after a verbal explanation of the rationale and aims of the study. It was emphasized that participation was on voluntary basis and that decline in participation would not affect their access to services.

Pre Testing

One hundred and fifty (150) mothers of children with cerebral palsy on treatment at Cerebral Palsy Centre, Lagos, Federal Neuro Psychiatric Hospital, Yaba and Adeyemo Special Needs School, Ibadan were recruited using the purposive sampling technique for the pre-testing. The mean age is 35.42 SD 6.54 (range 21- 60years). Lager percentage of the respondent (91.8%) were females and 8.2% were males. 63.3% were married, 18.4% were separated, and 18.4% were single. 28.6% were SSCE holder, 26.5% acquired post university degree, 20.4% were not educated, 16.3% have primary school leaving certificate, 4% were OND/Diploma holder. Caregivers were excluded if unwilling and not in a position to give informed consent.

Basic Instruction

The participants were notified that the index is strictly for clinical and academic purposes. Therefore, test-takers were encouraged to read the instructions carefully and respond to each statement of the index truthfully as there are no wrong or right answers.

Statistical Analysis

Correctly filled questionnaires were scored and subjected to Exploratory Factor Analysis (EFA) as this method of factor extraction is considered by many as more appropriate in the early stages of scale development. The criterion used to determine how many factors to retain was that of Kaiser (i.e. eigen values greater than 1 are retained), which is one of the most widely used (Adejuwon & Ibeagha, 2005). Two major statistical techniques were used for analysis, which includes correlation analysis (Pearson Product Moment Correlation) and Cronbach's alpha reliability (for test of internal consistency). All the inferential statistics were evaluated at 0.05 level of significance.

Total Item Reliability

The initial reliability was 0.541 Cronbach alpha. From the fourteen (14) items, nine (9) items were adjudge reliable and five (5) items were deleted due to poor reliability using < 0.3 criterion loading on the Total Item Correlation (ITC). After deleting the unreliable items, the scale achieved a reliability of 0.88 Cronbach alpha in this study meaning that eighty-eight percent of the respondent were consistently responded to the questionnaire (see Table 1).

Table 1: Showing the internal consistency (Reliability) Cronbach alpha and Total item statistics for CPSSS

Cronbach's Alpha	N of Items
.888	**9**

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
I don't have enough money to take care of my child	17.4490	69.378	.416	.914
There is a special person who is around when I am in need.	19.4694	54.588	.852	.843
My family really tries for me	16.7551	65.730	.804	.861
There is a special person with whom I can share my joys and sorrows	16.8163	63.611	.705	.869
People around me are willing to suggest help or information about my child's condition	19.1224	60.485	.678	.874
I get the emotional help and support I need from people around me.	18.6531	58.315	.361	.843
I get mocked due to my child's health condition	16.8163	63.611	.505	.869
People avoid me because of my child's condition	17.1424	61.485	.578	.874
My spouse help me in taking care of my child	18.5531	57.315	.661	.843
There is a special person with whom I can share my joys and sorrows	17.8163	62.611	.405	.912

Split half reliability

Split half reliability was determined was used to the determine internal consistency Cerebral Palsy Social Support Scale. The items were splited into equal halves and were further correlated. Split-Half reliability of part A (r = 0.74) and part B (r = 0.82) were reported respectively. Correlation between forms was (0.83). Spearman-Brown equal length Split-Half Coefficient was (0.91) and Guttman Split-Half Coefficient was (0.90) were reported. (See Table 2)

Table 2: Showing the split half reliabilities for CPSSS

Reliability Statistics

Cronbach's Alpha	Part 1	Value	**.740**
		N of Items	**4**[a]
	Part 2	Value	**.832**
		N of Items	**5**[b]
	Total N of Items		**9**
Correlation Between Forms			**.826**
Spearman-Brown Coefficient	Equal Length		**.905**
	Unequal Length		**.905**
Guttman Split-Half Coefficient			**.903**

a. The items are: I don't have enough money to take care of my child, There is a special person who is around when I am in need., My family really tries for me.

b. The items are: There is a special person with whom I can share my joys and sorrows, People around me are willing to suggest help or information about my child's condition, I get the emotional help and support I need from people around me..

Internal Consistency

Internal consistency of the CPSSS was derived from the Cronbach alpha analysis revealing the overall alpha value of 0.88, indicated that the whole scale is strongly reliably (see Table 3) and the dimensions or sub scales have meritorious reliability (Sub scale 1, α =.90, Sub scale 2, α =.72; Sub scale 3, α =.89).

Table 3: Factor loading and reliabilities of the components of CPSSS

Varimax Rotated Component Matrix^a			
	Components		
	Emotional/nformational support (α = .9)	Financial and Moral Support (α = .72)	Façade support (α = .89)
I get the emotional help and support I need from people around me.	**.98**		
There is a special person who is around when I am in need.	**.94**		
People around me are willing to suggest help or information about my child's condition	**.91**		
My family really tries for me	**.70**		
I don't have enough money to take care of my child		**-.89**	
My spouse help me in taking care of my child		**.81**	
There is a special person with whom I can share my joys and sorrows		**.68**	
People pretend to help but mocked me behind my back due to my child's health condition			**.95**
People show care but avoid me because of my child's condition			**.94**

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.

Step II: Exploratory Factor Analysis

An exploratory factor analysis was applied to explore the underlying dimensions of Cerebral Palsy Social Support scale. Cerebral Palsy Social Support Scale responses were submitted to an analysis of their principal components in line with Kaiser's method – eigenvalue > 1. As verified by KMO = .61, $X^2 = 428.42$, df = 36, $p<.001$, this suggest that the data matrix could be factorized. The principal axis factor extraction with varimax rotation produced a three factor solution that accounted for 88.27% of the variance in item responses. The factors yielded are emotional/informational support, financial - moral support and facade support. The factor loading for the items ranged from 0.68 to .98 which indicated that all the items loaded well on the factors precipitated.

Emotional/informational support: Items loading on component 1 are: item 1, 2, 3, and 4.
Financial/ moral support: Items loading on component 2 are: item 5, 6 and 7
Facade support: Items loading on component 3 are: item 8 and 9.

Step II: Validity Report

Construct Validity: Construct validity was accomplished through the convergent and discriminant validity. The overall index score on the Cerebral Palsy social support scale was significantly and positively correlated with Multidimensional Scale of Perceived Social Support (r = .45, p<.001). In addition, the subscale of emotional/informational support was positively correlated with financial/moral support (r= .30, p<.001). Facade support did not correlate with socio-emotional and financial moral support (See Table 4).

Table 4: Showing the Pearson Correlation of CPSSS and Multidimensional Social Support Scale indicating the Convergent Validity

	Mean	S.D	1	2	3	4	5
CPSSS	29.33	7.97	1	.93**	.42**	.48**	.45**
Emotional/Informational Support	15.27	6.26		1	.30*	.20	.62**
Financial/moral support	8.78	1.92			1	-.16	.16
Façade Support	5.29	2.82				1	-.22
MSPS	41.55	19.71					1

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

Administration

The test may be administered by psychologists, general medical practitioners, counselors and social workers. All parts of the test can be administered orally to persons with reading disability or visual impairment. The test taker is required to pick from options of 1 to 7 in response to the questions that ask the person how he/she feels.

Scoring Format

CPSSS is a seven point Likert response scale (1 to 7) with items that are directly and reversely scored. Items to be directly scored are items 1, 2, 3, 4, 5, 6, 7. Items to be reversely scored are items 8 and 9.

Norm

The overall mean score is 29.33. The average scores for the scale sub dimension were emotional/informational = 15.27; financial and moral support = 8.78 and Façade Support= 5.29. The Cerebral Palsy Social Support scale range of possible scores is within 9 - 63. High scores above the mean score denotes high emotional/informational support, financial/moral support and low façade support, while scores below the mean score denotes low emotional/informational support, financial/moral support and high façade support (see Table 5).

Table 5: Pearson correlation showing the relationship between cerebral palsy social support scale, MPSS and subscales cerebral palsy socio-support scale

	Mean	S.D	Norm scores 1 S.D above the mean
CPSSS	29.33	7.97	37.30
socio emotional support	15.27	6.26	21.53
Financial moral support	8.78	1.92	10.69
Façade (Stigmatized) Support	5.29	2.82	8.11

DISCUSSION

The study found that the cerebral palsy social support scale achieved a reliability of 0.88 Cronbach alpha which is acceptable for a newly developed scale (Nunnally, 1979). The construct validity yielded a 3 three factor subscales which made it more robust than the Multidimensional Scale of Perceived Social Support. Cerebral Palsy social support scale achieved convergence validity with Multidimensional Scale of Perceived Social Support while the subscale of socio-emotional support, financial support correlated with each other while stigmatized/faked support another approach to react to social support did not correlate with socio-emotional and financial support.

Conclusion

Results of the present study need to be interpreted with caution due to methodological limitations. As such there is need to provide supportive interventions for the caregivers to mediate the effects of caregivers burden. Large scale studies are also needed to establish the normative Social support values of caregivers. Additionally, there is a great need to constantly assess caregivers' Social support so as to detect those caregivers who need support at early phase of their child illness. Special emphasis should be on the screening for toxic support. Further, large scale, longitudinal studies which also include caregivers who reside in rural areas must be done to ascertain the perceived Social support states of caregivers.

Competing Interests

'*The author(s) declare that they have no competing interests'.*

Acknowledgements

Our heartfelt gratitude goes to caregivers for their cooperation during the study.

REFERENCES

Adejuwon, G.A. & Ibeagha, P.N.(2005). Adolescent behavioural outcome: Scale development and validation in Ibadan, Nigeria. *Journal of Social Sciences*. 10(2), 123-127.

Brehaut, C., Kohen, D. E., Raina, P., Walter, S. D., Russell, D. J., Swinton, M., O'Donnell, M., & Rosenbaum, P. (2004). The health of primary caregivers of children with cerebral Palsy: How does it compare with that of other Canadian caregivers. *Pediatrics.* 114 (2), 182-91.

Goffman, E. (1963). *Stigma; notes on the management of spoiled identity*. Englewood Cliffs, N.J., Prentice-Hall.

Gruetzner, H.M. (2001). *Alzheimer's: A caregiver's Guide and Sourcebook*. Wiley.

Hudson, A.L., Nyamathi, A., & Sweat, J. (2009) homeless youths' interpersonal perspective of health care providers. *Issues in Mental Health Nursing*. 29:1277-1289.

Mulvaney-Day, N.E., Alegria, M., & Sribney, W. (2007). Social cohesion, social support, and health among Latinos in the United State. *Social Science and Medicine*. 64(2): 477-95.

Nielsen, A. (2009). Loneliness and Social support in Adolescent boys with Autism. *Journal of Autism Development Disorder.* 40(2):218-26.

Nunnally, J.C. (1978). *Psychometric theory* (2nd ed.). New York: McGraw-Hill.

Ozbay, F., Johnson, D.C., Dimoulas, E., Morgan, C.A. (2007). Social Support and resilience to stress: From neurobiology to clinical practice. *Psychiatry*. 4(5): 35-40.

Sarafino, E.P (2002). *Health Psychology: Biopsychosocial interactions* (4th ed.). New York, NY: John Wiley & Sons,

Schopler, E., & Mesibor, G.B. (Eds.). (1984). *The effects of Autism on the family*. New York: Plenum.

Schopler, E., & Mesibov, G.B. (1984). *Autism in adolescents and adults.* New York: Plenum.

Taylor, S.E. (2011). *Social support:* A review. In H.S. Friedman (Ed.), Oxford Handbook of Health Psychology. New York.

Thompson, R.A. (2015). Social support and child protection: Lessons learned and learning. *Child Abuse & Neglect*. 41(1), 19-29.

Turney, K., & Kao, G. (2009). Assessing the private safety net: Social support among minority immigrant. *The Sociological Quarterly.* 50(4): 666-692.

Thompson, A., Fan, M.Y., Unutzer, J., & Katon, W. (2008). One extra month of depression: The effects of caregiving on depression outcomes in the impact trial. *International Journal of Geriatric Psychiatry,* 23(5):511-516.

Zimet, G.D., Dahlem, N.W., Zimet, S.G., Farley, G.K.(1988) The Multidimensional Scale of Perceived Social Support. *Journal of personality assessment*, 52(1). 30-41.