

## **Social Support, Satisfaction Level and Well-Being of Informal Caregivers of Physically Challenged Children in South-Western Nigeria**

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**Abstract:** This study examined the impact of social support and satisfaction level on the well-being of informal caregivers of physically challenged children in South-Western Nigeria. Data were collected using Social Support Scale (SSS) developed by George, Blazer, Hughes and Fowler, to measure caregivers' social support and satisfaction level. The 18-item versions of Ryff's psychological well-being scale were also used to measure caregiver's well-being. However, this study is based on data from a large study on determinants of well-being of informal caregivers of physically challenged children in southwest Nigeria. Results indicate that social supports predict well-being of informal caregivers. The results further indicate that adequate support enhances satisfaction level of caregivers with support received. Therefore, the study recommends that various avenues of social support to caregivers of physically challenged children be strengthened so as to bring about more satisfaction to caregivers.

**Key words:** Social support, well-being, caregiver and physically challenged children, satisfaction level, recommends

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### **INTRODUCTION**

Social support refers to the verbal and non-verbal information or advice, tangible aid or action that is proffered by social intimates or inferred by their presence and has beneficial emotional or behavioral effects on the recipients (Collins, 2007). It can also be broken down to make distinction between different categories of social support (Antonucci and Jackson, 1990). The types of social support include instrumental, emotional, informational, tangible aid, positive social interaction, affection and esteem (Yu *et al.*, 2004). Social support has been identified to play a significant role in individual's well-being (Kahn *et al.*, 2003) and the progress of a variety of chronic disease conditions (Bisschop *et al.*, 2004). Hogan *et al.* (2002) suggest that individuals with more supportive families or friends have a better health status and they recover faster from health problems, compared to persons who are less socially integrated.

The word caregiver denotes people who look after the well-being of physically challenged infants and young children. In developing countries like Nigeria where there is absence of community or long term care, informal caregivers provide almost all care to people living with disabilities (Ducharme *et al.*, 2005). In fact it is estimated that caregivers assume 70-80% of all care and support

given to people with disabilities. Informal caregiver's role to children with disability includes all activities that meet their physical, psychological and social needs. It also include providing emotional support and identity research, behavior management, supervision of rehabilitation exercises and other treatments, mobilization and advocacy for services and other resources, mediation with various professionals, control of the quality of the care, decision-making for the person and the development of strategies for role conflict management (Levine, 2006).

Social support plays an important role in mediating the outcome of care giving. Studies suggest that the greater the social support the less stress the caregiver may have and the more effective the care giving to the psychological well-being of physically challenged children (Chen and Greenberg, 2004). Caregiver decisions about the feeding of physically challenged children their level of satisfaction with life and willingness to seek advice during child illnesses as well as the number of individuals available to assist with domestic tasks are caregiving characteristics associated with social support. Social support of caregivers is an important variable influencing child growth, especially in low income families living in deprived conditions.

The roles that informal caregivers play are not only important to the people for whom they provide care but also the overall economy of the nation (AARP *et al.*, 2008). Informal caregiving comes with many personal rewards and satisfaction but also with emotional, physical and financial challenges (Cummins, 2001). Informal caregivers often go unnoticed and with less than adequate support at the local, state and national levels. Informal caregivers often derive satisfaction and fulfilment from their physically challenged children. However, care giving can be a physically and emotionally exhausting job and people who provide care to their disabled children often do not receive the training, guidance or support necessary to carry out their responsibilities effectively (Guberman *et al.*, 2005). The fact that caring for relatives children who are physically challenged is not considered an official job, informal caregivers often do not know who to contact for information and support for both themselves and for those for whom they provide care. In addition because their role as a caregiver is considered voluntary, the federal, state and local resources to assist them have traditionally been quite limited.

Well-being has been defined many researchers and such definitions include that of Negovan (2010) who stated that psychosocial well-being has four dimensions which are subjective well-being related to every day's events, subjective well-being related to faculty events, psychological well-being and social well-being. Subjective well-being according to Diener *et al.* (2005) refers to a person's cognitive and affective evaluations of his or her life. Subjective well-being composes of two main components which are a cognitive (satisfaction) and an affective (pleasant affect and low levels of unpleasant affect) (Andrews and Withey, 1976). More also, well-being is postulated to combine life satisfaction or how people think their lives turned out to be and affect or what they feel about their lives. Well-being is related to personal satisfaction, engagement, hope, gratitude, mood stability, meaning, self-esteem, resilience, contentment and optimism. Thus, the well-being of informal caregivers thus refers to the physical, social and behavioural comportments of parents and family members of a disabled child.

Families are a critical source of support for children with disabilities. Family members absorb the added demands on time, emotional resources and financial resources (Baker-Ericzn *et al.*, 2005) that are associated with having a child with a disability. Yet, rewards from having a family member with a disability such as personal and spiritual growth have also been noted (Scorgie and Sobsey, 2000). Caregivers who were more able to satisfy their basic needs and perform their daily activities,

reported lower levels of psychological symptoms if they perceived higher levels of social support (Demirtepe-Saygili and Bozo, 2011). The burden of care-giving to a disabled child if not shared equally by both parents may mount to marital disharmony and hence indicating the need to establish counselling sessions for both parents and a day care centre, to reduce the burden on parents (Baker-Ericzn *et al.*, 2005). Study reveals relationship between caregiving role and physical illness such as back pain, loss of weight weight, sleep disturbances anxiety, phobia and depression among parents of children with disabilities (Gathwala and Gupta, 2004). More importantly, greater unmet needs for services contributed to poorer mental health. Poorer access to health care also contributed to poorer mental and physical health. Unmet needs for services and out of pocket disability-related expenses appeared to pose difficulties for working age caregivers in affording the financial costs of health care for themselves (Parish and Ellisen-Martin, 2007). Adequate social support is important to family caregivers and is predictive of caregiving burden (Lai and Thomson, 2011). Such supports are capable of strengthening tangible services and resources such as home care services and community support resources as well as financial assistance and support for material needs. Support can also reduce depressing feeling among parents of physically challenged children and facilitate the social activity of caregivers to protect their psychological well-being (Cramm and Nieboer, 2011).

There are millions of informal caregivers in Nigeria who care for their children with severe disabilities. The roles they play are not only important to the people for whom they provide care but also for the overall economy of the nation (AARP *et al.*, 2008). Due to the role they play in the life of their children with disabilities, many of them are expose to harmful effect of caregiving. Although, caregivers often derive satisfaction and fulfilment from caring for their physically challenged children, the exercise can be physically and emotionally exhausting due to stress, anxiety and depression associated with the process. Besides there is no official training, guidance or support necessary to carry out their responsibilities effectively (Guberman *et al.*, 2005). More also, informal caregivers lack information and support for both themselves and their children with disabilities. Additionally, because their role is considered voluntary, the federal, state and local resources to assist them have traditionally been quite limited. Informal caregivers often go unnoticed and with less than adequate support at the local, state and national levels. Many of the physically challenged children and adults in Nigeria have poor psycho-social wellbeing and social outcome mainly due to psychological and physiological circumstances of the

caregivers (Lang and Upah, 2008; Okoye, 2010). The implication is that the process of rehabilitating children who because of physical disability, chronic illness or cognitive impairment are unable to perform certain activities on their own becomes a challenging one for the informal caregivers. Perhaps the most pervasive factors influencing well-being of physically challenged children is social support of caregivers expressed in the level of nutrition, healthcare, rehabilitation programme, facilities, etc. (Pongrapai *et al.*, 1998). Therefore, this study seeks to ascertain the impact of social support on the well-being of informal caregivers of physically challenged children in South-West Nigeria. The following research questions were postulated to guide the study: What is the impact of social support on the psycho-social well-being of informal caregivers? How satisfied are the caregivers with the support received?

**Theoretical framework:** This study is based on the Subjective Well-Being (SWB) theory which refers wellbeing to individual's current evaluation of his/her happiness. Such an evaluation is often expressed in affective terms; I feel good (Schkade and Kahneman, 1999). These theory proponents identified three main components of subjective well-being which are: life satisfaction, positive effect and negative effect. Subjective researchers identified correlates and determinants of subjective well-being, classifying them in six broad groups: personality factors; contextual and situational factors; demographic factors; institutional factors; environmental factors and economic factors.

Well-being may be evaluated by examining its cognitive and affective dimensions. If one frequently experiences a high level of life satisfaction and positive effect and seldom experiences negative effects then it could be said that one has a high level of subjective well-being. In contrast if one is seldom satisfied with one's life and frequently experiences negative effects, one can be said to have a low level of subjective well-being (Diener and Diener, 1997). Thus, the existing body of evidence suggests that subjective happiness within disability is a mix of internal characteristics and that of external factors that mitigates it. For example, most people define themselves as being happy, regardless of their material wealth (Diener *et al.*, 2005) while extremely minor incidents, influence estimate of subjective well-being (Schkade and Kahneman, 1999).

Most people assume that the external circumstances of others are powerful determinants of subjective well-being, in spite of the fact that such circumstances may have little effect on their own subjective well-being Schkade and Kahneman (1999). Though disability can have lasting and quite large effects on subjective well-being the presence or absence of good care giving

experiences will definitely moderate the people living with disability and their caregivers' perceptions and experiences of wellbeing.

## **MATERIALS AND METHODS**

The larger study employed an expost facto research design that involved 812 caregivers of children with disabilities selected from different special schools in the three states of Lagos, Oyo and Ondo of Nigeria. These states for administrative purposes are divided into local government areas and mostly occupied by yoruba speaking people and Lagos is the economic capital of Nigeria. The other two states are also economic centres where people across the federation ply their trades.

Multi-stage sampling was employed to randomly select three states from the six states in the Southwest geo-political zone. The second stage of the sampling involved random selection of two senatorial districts in Oyo and Lagos while one was selected in Ondo State. Children from various special schools that took part in the study were selected through stratified probability.

The Social Support Scale (SSS) developed by George *et al.* (1989) was used to measure caregivers' social support and satisfaction. Internal consistency has been reported at 0.64 for social support (Dunst, 1985). The scale consists of items covering such sources of support as the immediate family, relatives, friends and others in the family's social network, social organizations and specialized, generic professional services and other sources. The caregivers were asked to rate each source of support on a 5-point Likert scale (ranging from not at all helpful (1) to extremely helpful (5)). Past studies have indicated that the instrument is reliable (Dunst *et al.*, 1994). The caregivers' psycho-social well-being was measured using the 18-item versions of Ryff and Keyes (1995) psychological well-being scale. The scale has six subscales: autonomy, personal growth, positive relations with others, purpose in life and self-acceptance and environmental mastery. High scores indicate high level of psychological well-being. Earlier studies indicated that the scale has a high reliability co-efficient (Ryff and Keyes, 1995). A pre-test was carried out to ascertain the reliability and validity of the questionnaire. The pre-test involved a sample of 50 respondents selected from special schools that were not included in the main study. This was followed by fine tuning by necessary modifications. It was this fine-tuned copy that was used for data collection. Data collected were analysed through Statistical Package for Social Sciences (SPSS). Regression analysis and one way ANOVA were used to analyse research questions. Some of the items in the questionnaire were adapted and revalidated to fit into the Nigerian study.

## RESULTS AND DISCUSSION

Table 1-3 shows the findings on the objectives of the study on the impact of social support and satisfying level of informal caregivers of children with disabilities. To determine the impact of social support on the wellbeing of the informal caregivers, Table 1 shows that there were two models; social support model and social support level of satisfaction received from significant others in society.

Table 1 in the first model shows that social support predicts well-being of informal caregivers of physically challenged children. This is because significant level  $p < 0.05$  level of significance was achieved. Moreover, social support accounted for 28.8% direct impact in relation to well-being. In the second model social support and satisfaction level combined together have an impact on well-being of informal caregivers of physically challenged children. This is also because significant level  $p < 0.05$  level was achieved. Social support and satisfaction level when combined together accounted for 35.1% direct impact in relation to well-being of informal caregivers. The inclusion of the level of satisfaction with the level of social support increased the level of impact and prediction of sound wellbeing. In order to determine the level of social supports from significant others in society, a series of questions were asked and the responses are displayed in Table 2.

From Table 2, it shows that supports from different sources to informal caregivers were either found to be useful or not. Support from early childhood intervention programme has the highest score of 92.4% followed by spouse or partner 90.8% and other parents with 90.4%. More also, supports from social groups/clubs has 90% while support from spouse or partner relatives/kin scores 88.2%. Lowest supports comes from my spouse or partner's parents with 50.6% followed by my spouse or partner's friends 57.3% and my family or child's physician 60%. The implications of this result are that the majority of caregivers found some supports to be more useful than the other. All the sources are useful but useful in various degrees to caregivers. Table 3 reflects responses of respondents to questions on their satisfaction level with received supports.

Table 3 reveals level of satisfaction of caregivers from support received. Highest level of satisfaction of support to caregivers comes from spouse or partner's relatives/kin 94.8% followed by social groups/clubs

94.1%. Caregivers also received high satisfaction level from spouse or partners 93.8% parents and 93.5 from relatives/kin. The lowest satisfaction comes from my spouse or partner with 83% and my parents 85.5%. The implication of this table is that caregivers found every support from different sources satisfactory as long as the support is contributing to caregiving role. It also shows that no support is found to be a waste or non-relevant either emotional, material, psychological and informational. This as well proved the importance of social support to caregivers' well-being.

The discussions of this study are based on the findings and the theory adapted for the study. Findings indicate that social support received predicts psycho-social well-being and also adequate social support also enhances satisfaction level of informal caregivers. It could also be interpreted that lack of social support results in poor well-being while inadequate social support leads to low satisfaction level. Adequate social support from community and institutions can reduce negative effect of caregiving thereby providing a high level of life satisfaction which can be seen as a high level of subjective well-being. A satisfactory social support leads to positive outcomes on well-being of caregivers while a non satisfactory support tends not to have a significant impact on caregivers' well-being. Support must be seeing to have positive impact before it could be regarded as support whether it is solicited for or voluntary.

Support from early childhood intervention programme was the most helpful support which indicates that caregivers' need of support right from the onset when a child is confirmed to be physically challenged is of great importance. This is because many of the caregivers at this stage may not know the implication of this condition for the child and for the family as a whole. In fact many caregivers do not know what to do with their disabled children as they lack information about disability and rehabilitation. Support at this level is very essential as it will determine the overall well-being of the child. Other sources of support that were also helpful include that of spouse or partner, other parents, social groups/clubs and social groups/clubs. The implication of this is that supports from networks of family members, relatives and community are also very essential and critical in determining well-being of caregivers of children with disability.

Table1: Impact of social support and satisfaction level on well-being of informal caregivers

Models	SE	$\beta$	T	Sig.*	F-ratio	Sig.*	R	R <sup>2</sup>	Adj. R <sup>2</sup>
<b>Model 1</b>									
Social support	0.025	0.288	8.559	0.000	73.253	0.000	0.288	0.083	0.082
<b>Model 2</b>									
Social support	0.026	0.351	9.791	0.000	48.476	0.000	0.327	0.107	0.105
Level of satisfaction with support received	0.032	0.168	4.671	0.000	-	-	-	-	-

\*Significant at  $p < 0.05$

Table 2: Responses of respondents on social support received by informal caregivers of physically challenged children

Social support	Whether support was helpful or not (n = 812)			
	Not helpful		Helpful	
	Freq.	%	Freq.	%
My parents	205	25.2	607	74.8
My spouse or partner's parents	401	49.4	411	50.6
My relatives/kin	321	39.5	491	60.5
My spouse or partner's relatives/kin	96	11.8	716	88.2
Spouse or partner	74	9.2	738	90.8
My friends	289	35.6	523	64.4
My spouse or partner's friends	347	42.7	465	57.3
My own children	121	14.8	691	85.2
Other parents	78	9.6	734	90.4
Co-workers	78	9.6	734	90.4
Parent groups	98	12.0	714	88.0
Social groups/clubs	82	10.1	730	89.9
Church members/minister	246	30.2	566	69.8
My family or child's physician	325	40.0	487	60.0
Early childhood intervention program	62	7.6	750	92.4

Table 3: Respondents' responses on the level of satisfaction of informal caregivers with social support

How satisfied are you with support from these sources	Level of satisfaction (n = 812)			
	Not satisfied		Satisfied	
	Freq.	%	Freq.	%
My parents	118	14.5	694	85.5
My spouse or partner's parents	50	6.2	762	93.8
My relatives/kin	53	6.5	759	93.5
My spouse or partner's relatives/kin	42	5.2	770	94.8
My spouse or partner	138	17.0	674	83.0
My friends	57	7.0	755	93.0
My spouse or partners' friends	23	2.8	789	97.2
My own children	62	7.6	750	92.4
Other parents	46	5.7	766	94.3
Co-workers	47	5.8	765	94.2
Parent groups	59	7.3	753	92.7
Social groups/clubs	48	5.9	764	94.1
Church members/minister	80	9.8	732	90.2
My family or child's doctor	45	5.5	767	94.4
Rehabilitation centre/school for handicapped	73	9.0	739	91.0

Support becomes beneficial when it achieved the desired result. Such beneficial support should be the type that brings satisfaction to the beneficiary. Caregivers in this study found different supports from their sources very satisfying and support from spouse or partner's relatives/kin attracted the highest satisfaction level of caregivers. Other sources that give high level of satisfaction include support from social groups/clubs, my spouse or partner's parents, my relatives/kin and parent groups. The trend in this study is that adequate support from family members, relatives and groups within the community combined together to ensure the well-being of informal caregivers of children with physical disabilities. The well-being of caregivers of these children depends on the availability of a satisfying social support received from the sources available to them.

In relation to subjective well-being theory of Schkade and Kahneman (1999), inference can be made to the impact of social support on well-being of informal caregivers of physically challenged children. According to the theory, environmental and institutional factors are very important in psycho-social well-being because they shield individuals from the harmful effect of stress. However, emotional, informational, community, governmental and non-governmental supports are all products of environment that are been provided by societal institutions and which are very essential in ensuring well-being of informal caregivers. Overall well-being of caregivers of children with disability could be enhanced through appropriate and satisfactory supports from various institutions within the society. This supports also has an indirect effect of ensuring well-being of these children and making them to live a better life like their non-disabled children. These findings in agreement with Demirtepe-Saygili and Bozo (2011) who submitted that caregivers who were more able to satisfy their basic needs and perform their daily activities reported lower levels of psychological symptoms because they received enough social support. The result is also in support of the study on quality of social supports as it was demonstrated in the study of Lai and Thomson (2011) who demonstrated that perceived adequacy of social support is important to family caregivers as it lessens caregiving burden. Kaufman *et al.* (2010) also corroborate the findings of this study that social support (the availability of persons with whom to talk or to socialize and the receipt of feelings of positive regard and self-esteem from others) were predictors of the life satisfaction among caregivers.

More also, Tsai and Wang (2008) in agreement with this study affirmed that mothers with intellectually disabled children had a rather high level of strain as result of inadequate social support.

## CONCLUSION

The literature and the findings of this study have considerably shown the contributions of social support to well-being of informal caregivers of children with disabilities. The findings show that caregivers' need of support is very important and that not just any support but adequate support that leads to satisfaction level. Caregiver's support from various sources was found to be helpful in reducing level of stress among caregivers thereby ensuring their overall well-being. Support for caregivers can be mobilized from family and friends, community and governmental institutions in a manner that

such support is helpful and satisfying to the caregivers. Support can also be in the form of services render to caregivers in the form of health promotion talk, making respite services available at an avoidable cost and counselling services to caregivers. Support can also be monetary assistance (giving directly to caregiver for maintenance of their disabled children) which can reduce financial burden of informal caregivers. There is need for the governments in these states to improve on the existing welfare programme that can strengthen these sources of support to informal caregivers.

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