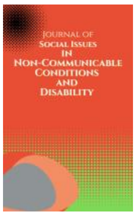

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Factors influencing caregiving burden of families supporting children living with down-syndrome in Ibadan

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Abstract

Down syndrome is a genetic condition affecting individuals worldwide, including in Ibadan, Nigeria. However, the experiences of families caring for children with Down syndrome remain underexplored, particularly in terms of caregiver burden. This study investigates the challenges faced by caregivers in Ibadan, examining how awareness and societal stigma influence their stress levels. A cross-sectional survey was conducted with 120 randomly selected family caregivers using the Caregivers' Burden on Children with Down Syndrome Questionnaire. The survey assessed socio-demographic factors, caregiver burden, and societal attitudes toward Down syndrome. Data analysis, using descriptive statistics and Pearson Product Moment Correlation (PPMC) at a 0.05 significance level, revealed key insights. The average caregiver age was 54.6 years, with most participants having tertiary education. Findings showed a strong correlation between caregivers' awareness of Down syndrome and their stress levels ($r = .713, p < .05$), as well as between societal stigma and caregiver stress ($r = .641, p < .05$). Additionally, a combined analysis indicated that awareness and stigma together significantly impacted stress levels ($F (2, 117) = 86.413; R = .821, R^2 = .824; p < .05$). These findings highlight the need for increased awareness and respite care programs for families of children with Down syndrome in Nigeria. Afrocentric care practices, such as Ubuntu and the wheel-of-life model, should be integrated to destigmatize families and support caregivers in this context.

Key words

Afrocentric, caregiver, children, Down syndrome, Nigeria,

Key points

1. The experiences of families caring for children with Down syndrome remain underexplored.
2. Findings showed a strong correlation between caregivers' awareness of Down syndrome and their stress levels ($r = .713, p < .05$).
3. A combined analysis indicated that awareness and stigma together significantly impacted stress levels ($F (2, 117) = 86.413; R = .821, R^2 = .824; p < .05$).
4. Afrocentric care practices, such as Ubuntu and the wheel-of-life model, should be integrated to destigmatize families and support caregivers.

Introduction

Down syndrome is a situation in which a child is born with more copy of their 21st chromosome. This account for slowness in physical and cognition growth and deficits. Several of the deficits are chronic or life-long and they can also shorten life expectancy. Therefore, people born with Down syndrome can live healthy and promising lives (Gill, 2019). All the people born with Down syndrome have some level of learning defect and therefore need special training assistance as they move on in life. The families of people born with Down syndrome require social and corporate help in order to assist and aware of their predicament and its related problems (Mbazima, 2016). The task of carers is crucial in assisting persons with disability in maintaining their relationship to the community in order to avoid total extermination from the community. However, the role assigned to the carers with dynamics in routine and period spent in caring and usually without enough attention and help within hospital settings and social connections may directly affect areas of their family and social life and indirectly good quality of life. Persons with physical disability and reliance on daily life survival that need additional physical ability from caregiver which henceforth resulting in more stresses (Barros, De Gutierrez, Barros, Santos, 2017). The psychological balance of family living with Down syndrome children has a significant impact on a child's growth nevertheless of the child's cognitive performance (Mona et al 2019; Mugumbate & Mel, 2020).

The despair of a caregiver results from a disturbance in tackling persons with physical reliance and cognitive deficit, the focus of attention and care aim areas of care giving burden consist of usual changes, reduced social and professional life, monetary loss, overwork and the management of difficult attitudes of the person being look after. The subjective areas of this stress care linked to the carer's perception feeling, responsibilities and positive and negative feelings. Evidence of fear and slow self-esteem are documented by the carers of persons with Down syndrome. The carer is the sole individual with complete or higher task in the care given to the person being looked after, and zero financial reward is granted for the care given by the family members, women are at very risk on account of taking the role of primary caregiver in most homes. Caregivers carried along with them the psychological, physical and monetary implication as well as reductions on social and leisure enjoyments (Momet al, 2019).

Down syndrome, a genetic condition resulting from an extra copy of chromosome 21, presents unique physical and cognitive challenges that require specialized care and attention. Families of individuals with Down syndrome often bear the primary responsibility for their care, a task that can be both rewarding and demanding. In the Nigerian context, caregivers encounter a myriad of socio-economic, cultural, and healthcare-related challenges that contribute to the overall burden they experience. Ibadan, as one of Nigeria's major cities, is not immune to the global occurrence of Down Syndrome. The disorder arises from a genetic anomaly, where individuals have an extra copy of chromosome 21. This additional genetic material affects physical and intellectual development, leading to distinctive facial features and potential health complications. In Ibadan, societal awareness and acceptance of Down Syndrome are improving, but there remains a need for increased education and understanding. Families grappling with a Down Syndrome diagnosis often encounter social stigmas, misconceptions, and limited resources for proper care and support. Caregivers mostly face the precarity of limited specialized healthcare facilities catering to individuals with Down Syndrome. This lack of access can hinder early interventions and tailored medical care, placing additional strain on caregivers. Educational resources for individuals with Down Syndrome are often insufficient. Stigmatization of individuals with Down Syndrome persists in Ibadan, leading to social isolation and discrimination. The financial burden of raising a child with Down Syndrome can be overwhelming. Many caregivers in Ibadan face challenges in accessing financial support, medical assistance, children living with down syndrome seemed like not part of the entire community and custodian homes. It was in the mid twentieth century that families, doctors, scientists and non-governmental organisations start to support people with Down syndrome managed to start developing the way individual with Down syndrome and other abnormalities were perceived and managed by the community. The birth of a child with multiple disabilities often evokes a mix of sadness, grief, and disappointment within the family, which can negatively affect their ability to accept and support the child (Van Riper, Ryff, & Pridham, 2012; Mugumbate & Mel, 2020). Down syndrome can impinge intellectual capacities in many ways, but it often results in minor to moderate intellectual damage. Children born with Down syndrome display slowness in speech and motor skills and may require assistance with personal hygiene, such as bathing and brushing which are usually complemented by caregivers. Children born with Down syndrome sometimes might have difficulties following class times-table due to frequent doctor appointments, including difficulties listening in the class and the need for more time and help with classroom. The quality of life with deficits has features for daily living and continuous care related not only the tasks of the daily life survival but in addition to training and recovery process of these person. Therefore, due to the nature of the children with Down syndrome the caregiver plays a pivotal role in giving them adequate care. This paper investigated the caregivers' burdens of care of children living with Down syndrome in Ibadan Metropolis.

Method and design

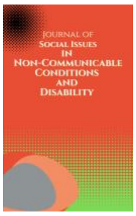
Study Design

The study utilized a descriptive research design because no manipulation of variables of interest was involved. The study was undertaken to examine the caregivers' burden of children born with Down syndrome. The target respondents for this study were sixty (60) instructors at Andrew Foster Memorial College (Deaf), Onireke, Ibadan, and sixty (60) teachers at Cheshire Home for the Handicapped, Ijokodo, Ibadan. Two schools for the disabled in Ibadan, Oyo State, were purposively selected for the study: Andrew Foster Memorial College (Deaf), Onireke, Ibadan, and Cheshire Home for the Handicapped, Ijokodo, Ibadan. All teachers of students living with Down syndrome in the selected schools were purposively sampled. The instruments for the study were designed for the teachers of children with Down syndrome.

Simple percentages were used to analyze the demographic data and teachers' questionnaires, while Pearson Product-Moment Correlation (PPMC) was adopted to establish relationships among the independent and dependent variables of the study at a 0.05 level of significance. All principles governing human research ethics were observed, including confidentiality, voluntariness, and ensuring no harm to participants. Informed consent was obtained from the respondents. Ethics approval was obtained from the University of Ibadan/University College Hospital, Ibadan Ethics Review Committee (Ethics number: UI/EC/22/0351).

Ethics Approval: Ethical approval for the study was granted by the Institutional Ethical Review Board (for blind review) under protocol number UI/EC/22/0351. Prior to administering the questionnaire, informed consent will be obtained from each participant to ensure voluntary participation and adherence to ethical standards. Participants will be fully informed about the purpose, objectives, and procedures of the study, as well as their rights to confidentiality, anonymity, and the option to withdraw at any point without repercussions. By securing informed consent, the study aligns with ethical research practices, safeguarding the well-being and autonomy of all respondents. This process enabled the participants to be aware of their involvement in the study and agree to share their experiences and insights freely, fostering transparency and trust between the researcher and respondents. Ethical compliance is a core element of the study, upholding the integrity and reliability of the research process.

Data analysis: To investigate the relationships between the independent and dependent variables, Pearson Product-Moment Correlation (PPMC) was employed. This statistical method was chosen for its ability to measure the strength and direction of linear relationships between variables. The analysis was conducted at a 0.05 level of significance, ensuring that the findings were statistically valid and meaningful. By using PPMC, the study was able to identify significant correlations between key variables, offering valuable insights into the factors influencing the caregivers' burden in the context of children born with Down syndrome. This approach allowed for a robust examination of the data, ensuring that the conclusions drawn were supported by sound statistical evidence, enhancing the reliability of the study’s outcomes.



Results

Table 1 Socio-demographic characteristics of caregivers

Socio-demographic characteristics	Variables	Frequencies	Percentage
Age	20-30	35	29.2
	31-40	60	50.0
	41 and above	25	20.8
Sex	Male	51	40.8
	Female	69	59.2
Types of family	Polygamous	45	37.5
	Monogamous	75	62.5
Educational status	Diploma	52	43.3
	University degree	58	48.4
	Master’s degree	10	8.3
Religion affiliation	Christian	41	34.2
	Muslim	70	58.3
	African religion (AR)	9	7.5
Ethnic group	Yoruba	70	58.3
	Hausa/Fulani	25	20.8
	Igbo	20	16.7
	Others	5	4.2
Years of experience	1-5 years	45	37.5
	6-10 year	51	42.5
	11-15 years	24	20.0

In terms of age, the majority (50.0%) were between 31-40 years old, with fewer respondents in the 20-30 years (29.2%) and 40+ years (20.8%) age groups. Gender-wise, there were more female respondents (61.5%) than males (40.8%). Regarding family type, 37.5% of respondents came from polygamous families, while 62.5% were from monogamous families. In terms of educational qualifications, most had a first degree (48.4%), followed by those with diplomas (43.3%) and master's degrees (8.3%). Religion-wise, 58.3% were Muslim, 34.2% were Christian, and 7.5% followed other religions. Ethnically, the majority were Yoruba (58.3%), followed by Igbo (16.7%), Hausa (12.5%), Fulani (8.3%), and others (4.2%). Lastly, in terms of work experience, 42.5% had 6-10 years of experience, 37.5% had 1-5 years, and 20.0% had 11-15 years of experience. .

Hypotheses Testing

Hypothesis 1

H$_0$1 There is no significant relationship between effects of Down syndrome and burden of caregivers on children with Down syndrome in Ibadan Metropolis

Table 2 Pearson correlation showing significant relationship between effects of Down syndrome and burden of caregivers on children with Down syndrome in Ibadan Metropolis

Variable	Mean	Std. Dev.	n	r	P	Remark
Burden of caregivers	21.23	5.44	120	.713	.001	Sig.
Effects of Down syndrome	14.86	3.11				

Table two shows that there was significant relationship effects of Down syndrome and burden of caregivers on children with Down syndrome: ($r = .713$, $n= 120$, $P < .05$).

Hypothesis 2

H$_0$2 There is no significant relationship between societal attitude and burden of caregivers on children with Down syndrome in Ibadan Metropolis

Table 3 Pearson correlation showing significant relationship between societal attitude and burden of caregivers on children with Down syndrome in Ibadan Metropolis

Variable	Mean	Std. Dev.	n	r	p	Remark
Burden of caregivers	21.23	5.44	120	.641	.000	Sig.
Societal attitude	15.22	4.01				

Table three indicates that there was a significant relationship between societal attitude and burden of carers on children born with Down syndrome; ($r = .641$, $n= 120$, $p < .05$). This finding is in line with Erikaleite et al (2021), who observed that the caregivers had low quality of life, and knowledge of the factors that contribute to this may enable a good performance of the carers in terms of care.

Hypothesis 3

H$_0$3 There is no joint significant relationship between independent variables (effects of Down syndrome and societal attitude) and burden of caregivers on children with Down syndrome in Ibadan Metropolis**.**

Table 4 Summary of Regression Analysis among Independent variables (effects of Down syndrome and societal attitude) and burden of caregivers on children with Down syndrome in Ibadan Metropolis.

Model		**Sum of Squares**	**df**	**Mean Square**	**F**	**Sig.**
Regression		943.113	2	471.557	86.413	.000
Residual		638.522	117	5.457		
Total		1581.635	119			

R=.821, R^2 = .824, Adj R^2 =.384

Table four shown that there was a joint relationship between independent variables (effects of Down syndrome and societal attitude) and the stress of carers on children born with Down syndrome was significant (F $_{(2, 117)}$ = 86.413; R = .821, R^2 = 824; P < .05). About 82% of the difference was estimated for by the independent variables. Thus, the two variables are good predictors of stress of carers on children born with Down syndrome.

Discussion

The paper revealed that most parents eagerly expect the birth of a healthy child however, on account of this expectation, initial diagnosis of disability is seen as the shattering of an ideal. Parent and other family members may witness a diverse of feeling once confronted with that very important change stemming from someone close to the family having a disability (Ross and Severe, 2010). Parents who serve as caregivers perform hospital function without adequate knowledge in medical training in health care system. The duties of care giving as well as the lack of preparation, guidance and support, nullify their physical and emotional health as well as their monetary capabilities. The paper sought to test if there is no significant relationship between effects of Down syndrome and burden of caregivers in Ibadan metropolis. The result revealed that there was an important relationship between effects of Down syndrome and burden of caregivers in Ibadan metropolis. The finding is consistent with the research carried out by Cheesman et al, 2006; Mbazima, 2016) who found out that the performance of mature students is better than the performance of younger students. They also found that students who receive financial assistance outperform others who do not receive financial assistance in the Anglophone Caribbean region.

Other results of the research indicated that enhancing the presence of professional cares, the provision of direction and counseling and social cohesion may assist to solve problems of nursing a person born with Down syndrome (Amna et al 2021; Mugumbate & Mel, 2020). It is crucial to ask from parents in terms of social support and to provide emotional help to the families with disabled pupil to minimise the care stress of families and also good parenting is vital for child's cognitive, physical, social and psychological growth and also the emotional balance of parents and families living with Down syndrome children has a serious influence on the children living with Down Syndrome. The research showed that the primary attention of proactive intervention practices for these children and their families (Buckley et al 2012;

Murugasen et al., 2024). Recent proactive measure has been closely connected to the opposition that interventions that directly involve families are positively impacted in enhancing children's training and growth than those that do not. The emergent of chronic diseases such as inborn abnormality, heart defects, hypothyroidism and immunological problems can influence the several areas of the life of caregivers of children with Down syndrome leading to tiredness, solatory, burden and stress. The stress occurs from a disturbance in solving individual's physical reliance deficit, the focus of attention and care. The main aspects of care giving stress consist of normal changes, reduce social and professional life, financial meltdown, overwork and the monitoring of difficult behaviors of the person being looked after (Beatriztar 2020).
The paper also found out that there was a significant relationship between societal attitude and stress of carers on children born with Down syndrome in Ibadan Metropolis.The above finding corroborated the study carried out by (Erikaélite et al, 2021) They observed that the carers had poor quality of life, and information about the factors that contributes to this may enable an outstanding care to the carers. The quest of the parents born with Down syndrome is markedly higher because the family must actively engage in the care of the child due to the delay in growth, the limitations in the task of daily survival related to self-care such as bathing, personal cleaness, physical fitness and areas that linked to health education and leisure (Baros et al 2021). There is heavy burden witnessed by parents of pupil born with Down syndrome and this should be a focus of giving priority to the children service provider that may be attending to this child enhancing social supports and advocacy to stakeholders.

The paper also sought to test if there is no significant joint relationship between independent variables (effects of Down syndrome and societal attitude) and stress of carers on pupil born with Down syndrome in Ibadan Metropolis. The result revealed that there is joint relationship of independent variables (effects of Down syndrome and societal attitude) and stress of carers on pupil born with Down syndrome in Ibadan metropolis was significant. The finding is in tandem with the study conducted by (Jeona, Myong & Koo, 2015) They opined that the many problems encountered by the caregivers are unanimously known as the caregiver stress, The caregivers had the feelings of aches and pains on account of serious physical task of caregiving. They also experienced feeling of wrongdoing about the child's situation. On account of difficulty in maintaining balancing between family and vocation, heavy monetary commitments as well as perceived lack of knowledge and awareness about the possible alternative ways for the management of the child.

Recommendations

Ensuring the inclusion of children with Down syndrome within education, healthcare, and social services requires a multi-stakeholder approach to policy development. Current gaps in legal awareness among caregivers must be addressed through targeted government and private-sector initiatives that inform them of their rights and available resources. Advocacy efforts should not merely push for policy development but actively monitor and enforce their implementation to safeguard the rights of individuals with Down syndrome. True inclusivity means embedding these rights into systemic structures, rather than relying on fragmented interventions. In an era where digital solutions can enhance accessibility, technology must be leveraged to support both caregivers and children. Mobile applications, telehealth services, and online support networks could provide real-time information on healthcare, education, and emotional well-being. These innovations are particularly vital for families in rural and underserved areas, where access to specialised services remains limited. However, digital interventions must be developed with an awareness of infrastructural and literacy barriers that may hinder effective utilisation.

The economic burden on caregivers cannot be ignored. Many struggle to balance employment with caregiving responsibilities, often facing workplace discrimination or financial instability. Employers and policymakers must work collaboratively to implement flexible working arrangements, job security measures, and vocational training opportunities that enable caregivers to sustain their livelihoods. Without such protections, families are left in precarious situations, reinforcing cycles of poverty and exclusion. Additionally, caregiving must be understood within a cultural context. Policies and support services must be tailored to accommodate diverse beliefs about disability, health, and family roles. Generic approaches risk alienating communities where stigma and misinformation prevail, ultimately undermining efforts to support children with Down syndrome. This necessitates a culturally competent framework that is responsive to the lived realities of families.

Finally, caregiving is rarely an individual endeavour—it extends to siblings and extended family members. A truly effective support system must engage the wider family unit, ensuring they understand Down syndrome, their caregiving roles, and how best to support the primary caregiver. Holistic, community-driven strategies are essential in fostering resilience and reducing caregiver burden. Without structural change, inclusion remains an aspiration rather than a reality.

Conclusion

The findings of this study underscore the urgent need for a shift in societal attitudes toward disabilities, particularly Down syndrome, across the African region. Deep-seated cultural beliefs, stigma, and limited awareness continue to isolate both children with Down syndrome and their caregivers, exacerbating stress and limiting access to essential services. Caregivers not only bear the emotional and financial burden of their child's medical needs but also face discrimination and social exclusion, which further deteriorates their mental well-being. To address these challenges, disability awareness must be integrated into educational curricula and national discourse to foster a culture of inclusion. Policy interventions should prioritize accessible healthcare, inclusive education, and respite care services, ensuring caregivers receive adequate support. Collaboration between governments and NGOs is crucial to strengthening healthcare infrastructure, training professionals, and expanding mental health resources for caregivers. A holistic, multi-sectoral approach is essential to reducing caregiver burden and promoting the rights and dignity of children with Down syndrome across Africa.

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