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Illness Intrusiveness in Parental Figures Caring for Ill Children

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Abstract

Introduction

Illness intrusiveness in a parental figure or a family caregiver is when the disease or illness-related factors disrupt the valued lifestyle, activities and interests of the caregiver. Illness intrusiveness can occur in a parental figure who is primarily responsible for caring for a sick child, and it is usually worse when the child is living with a chronic disease. Illness intrusiveness distorts the parental figure's life and inadvertently the child's quality of life.

Methods

A descriptive cross-sectional study was conducted at the Paediatric, Haematology and Family Medicine outpatient clinics of the University College Hospital, Ibadan (UCH), between June and December 2017.

The participants were children with Sickle Cell Disease (SCD) and healthy or acutely ill children with their respective family caregivers or parental figures. The caregivers or parental figures were administered the Illness Intrusiveness Rating Scale (IIRS) questionnaire while the children were administered the Pediatric Quality of Life (PedsQL) questionnaire.

Results

Seventy (70) children living with SCD and 70 healthy or acutely ill children and their respective parental figures participated in this study.

Mothers constituted the majority of the primary caregivers for both children living with SCD (74.3%) and those not-living with SCD (80.0%). The parental figure of SCD children had higher (worse) scores for illness intrusiveness than the non-SCD caregivers (26.17 ±15.8 versus 26.11±11.6; p=0.000). The correlation between the caregiver's illness intrusiveness score and PedQoL is stronger and more significant for the SCD group (r=.610; p=0.000 versus r=.383; p=0.001), particularly for Physical health-related PedQoL and School-related PedQoL.

Conclusions

Parental illness intrusiveness is a measure of adjustment to the caregiving process by the parental figure and it contributes to the child's quality of life and the prognosis of the disease.

Keywords: Illness, intrusiveness, parental, chronic, QoL, Paediatrics

1. Introduction

Illness intrusiveness explains how disease-related factors can determine the patient's quality of life or that of their caregivers.[1,2] The interpersonal relationships within a family can be influenced by the presence of a sick child. Specifically, the relationship between the parents and the relationship between the parent and any other offspring may be affected adversely.[3,4] The organisations within the family raising a sick child are less favourable.[1] The ill child's presence also reduces the ability of the primary parent or caregiver to participate in social activities outside of the family.[1,3,4] Illness intrusiveness is when a disease or the disease's treatment-related factors disrupt valued lifestyle, activities and interests, especially for chronic disease.[2] Illness intrusiveness is about how a disease and treatment factors influence subjective well-being and interfere with meaningful activities of life and daily living.[1,2] The illness intrusiveness scale assesses three main aspects of life, which are "relationships and personal development", "intimacy", and the domain of "instrumental life".[5] Relationship and personal development entails family or social relations, self-expression and improvement, religious expression, community and civic involvement, or passive recreation.[2,5] The intimacy domain encompasses the relationship with an intimate partner including the sexual life.[2,5] The domain of Instrumental life, assesses the health, work, financial and active recreation of an individual.[1,2,5]

Sickle Cell Disease (SCD) is one of the most common childhood-onset, single-gene disorders, affecting primarily

people of African descent.[1] In West African countries such as Ghana and Nigeria, the frequency of carriers is 15% to 30%.[3] In Nigeria, with an estimated carrier prevalence of 24%, 20 per 1000 births are estimated to be affected by SCD, resulting in 150,000 children with SCD born annually in Nigeria.[3]SCD crisis or other manifestations of SCD in children can have a widespread impact on both the functioning of the individual diagnosed with the illness and their families, particularly the primary caregiver.[1] SCD is a chronic disease in Paediatrics marked by recurrent acute crises, repeated hospital visits and at times life-threatening complications.[6,7] It is therefore not surprising that caregivers of children with SCD who have high levels of care burden have alarmingly high rates of illness intrusiveness.[2,5,8] Studies have suggested parents of young children with SCD experienced clinically significant levels of caregiver's illness intrusiveness.[1,5]

Illness intrusiveness has been reported as an integrated factor in predicting overall functioning in caregivers caring for a child with SCD or another chronic illness.[1,5,8] The illness intrusiveness in a caregiver can influence the Health-related quality of life (HRQL) of the child being cared for, particularly for a child with a chronic disease, like SCD. Generally, the HRQL of children with sickle cell disease is poor.[1,9] Specifically studies have found that children with SCD experience more significant limitations in general health and physical functioning, more limitations in their academic functioning and social activities attributed to their physical health, and more behavioural and emotional problems.[1,9,10]Living with SCD has been associated with features of poor HRQL which can be worsened when the caregiver experiences marked illness intrusiveness. [1,9,10] It is known that parents or the primary family caregivers of children with chronic illness may experience more features of illness intrusiveness in contrast to those caring for children with acute disease.[8-10]

This study compared illness intrusiveness in the family caregivers of SCD children and those caring for children with acute disease and also accessed the association between caregiver's illness intrusiveness and the children's HRQL.

2. Method

2.1 Study Site

The study was conducted at the Paediatric, Hematology and Family Medicine outpatient clinics of the University College Hospital, Ibadan (UCH), South-west Nigeria. The Paediatrics and Hematology departments are prominent tertiary centers for most children with SCD living in southwest Nigeria where expert health care is provided by specialists. The Family Medicine department is the entry point for most patients presenting to the UCH, where primary and secondary health care services are provided to patients of all ages and both genders of which approximately 30% are children under the age of 18 years.

2.1 Study Design

The study was a descriptive cross-sectional study using a consecutive sampling method for participant selection.

2.2 Study Participants and Sampling

The participants were children with Sickle Cell Disease (SCD) and healthy or acutely-ill children with their respective family caregivers or parental figures. The children with SCD were first selected and matched with a comparison group of acutely-ill children using the age at a variation of 5 years. The primary caregivers of both groups of children were identified and recruited for the study.

The SCD and the acutely-ill patients were children between the ages of 8 to ≤ 18 years. The primary caregivers for both groups were adult relatives or parental figures who were directly involved in the informal and intimate caregiving roles at home. The children with SCD were those in stable clinical condition presenting to the Paediatric haematology clinic or the Hematology department day-care clinic of UCH for routine follow-up visits. The healthy or acutely ill but stable children were those presenting to the Family Medicine clinic. The acutely-ill children were those with uncomplicated respiratory tract infection, uncomplicated malaria, uncomplicated allergic disorder or simple skin disease which constitute the common pattern of illness seen at the Family Medicine clinic. The healthy children were those on follow-up visits, on referral to another unit in the hospital, for routine immunization or medical certificate of fitness.

Children whose parental figure consented to the child's participation were selected after assent was obtained from the child. Consent for participation as a caregiver was also directly sought from each caregiver for both groups of children.

2.3. Data Collection

Ethical approval was obtained from the Ethical Review Committee of the University of Ibadan/University College Hospital, Ibadan. Parental consent and permission for each child's participation were obtained after which assent was obtained from each child.

A structured interviewer-administered questionnaire was administered to consecutive consenting caregivers and assenting children. The questionnaire contains socio-demographic data and family settings.

The caregivers were administered the Illness Intrusiveness Rating Scale (IIRS) while the children were administered the Pediatric Quality of Life (PedsQL) questionnaires.

The illness intrusiveness rating scale (IIRS) is a 13-item tool with an internal consistency at Cronbach's α 0.92 and test-retest reliability of 0.95.[1,2]

The 13-item is divided into 5subscales which measure 5 aspects of life that caring for an ill person can intrude on as perceived by the caregiver.

The IIRS subscales measure 1. Physical well-being and diet; 2. Work and finances; 3. Marital, sexual and family relations; 4. Recreation and social relations and 5. Religious or spiritual activities aspects of life.

The IIRS is a self-report instrument that utilizes a 7-point Likert scale ranging from 1 (not very much) to 7 (very much). The subscale scores are the mean of the items within each subscale. The total perceived intrusiveness score was also generated by summing the individual items of the 5 subscales. The higher the score of the sub-scale or the overall scores of the IIRS the more the illness intrusiveness.

The Pediatrics Quality of Life (PedsQL) tool is a questionnaire used for measuring health-related quality of life (HRQOL) in healthy, acutely ill or chronically ill children and adolescents.[11,12]

The PedsQL scale is a 23-item tool for measuring HRQOL in children aged 2-18 and we used the Child Self-Report version for children aged 5-18. The PedsQL is a validated and reliable tool with a Cronbach's alpha of 0.88 measuring the Physical, Emotional, Social and School Functioning in a child.

The 23-item PedsQL scales were designed to measure the core dimensions of health as delineated by the World Health Organization, as well as role or school functioning. The PedsQL can be categorized into 4 multidimensional Scale measures; Physical Functioning (8 items), Emotional Functioning (5 items), Social Functioning (5 items) and School Functioning (5 items).

The 23-item PedsQL scale utilizes a 5-point Likert scale of 0 (never a problem) to 4 (almost always a problem).

The subscale scores of the PedsQL are the mean of the items within each subscale. The higher the scores of the sub-scales or the overall score of PedsQL the worse the QoL.

2.4 Data Analysis

The data was analyzed using the Statistical Package for Social Sciences (SPSS) software version 23.

Chi-square statistics was conducted to test for association between categorical variables while the student t-test and correlation analysis was used to compare means of continuous variables.

Analyzed data is presented in tables with a p-value of <0.05 taken as a statistically significant result.

3. Results

A total of 140 children comprising 70 children with SCD and 70 healthy or acutely ill children and their respective caregivers participated in this study.

Table 1 depicts the largest proportion of the primary caregivers for both the sickle cell and non-sickle cell children were their mothers (74.4%) and (80.0%) respectively.

The highest proportion of the caregivers in both groups had tertiary educational attainment at (45.7%) and (55.7%) in the sickle cell and non-sickle cell groups respectively while 75.7% and 64.3% of caregivers in the sickle cell and non-sickle cell groups were self-employed respectively.

Table1.Characteristics of the parental figures

Caregivers characteristics	SCD children n (%)	Non-SCD children n (%)	p-value
Relationship with child			
Mother	52((74.4)	56(80.0)	0.439
Father	11(15.7)	11(15.7)	
Grandmother	6(8.5)	2(2.9)	
Stepmother	0(0.0)	0(0.0)	
Older Sister	1(1.4)	0(0.0)	
Aunty	0(0.0)	1(1.40)	
Gender			
Male	22(31.4)	11(15.7)	0.029
Female	48(68.6)	59(84.3)	
Educational attainments			
Primary	20(28.6)	14(20.0)	0.163
Secondary	18(25.7)	17(24.3)	
Tertiary	32(45.7)	39(55.7)	
Occupation			
Self-employed	53(75.7)	45(64.3)	0.163
Civil servant	16(22.9)	25(35.7)	
Retired	1(1.14)	0(0.0)	
Marital status			
Single	43(61.4)	4(5.7)	0.000
Married	24(34.3)	62(85.6)	
Separated	1(1.14)	1(1.40	
Widowed	2(2.9)	3(4.3)	
Ethnicity			
Yoruba	68(97.1)	57(81.4)	0.010
Igbo	2(2.9)	10(14.3)	
Hausa	0(0.0)	3(4.3)	

There is a statistically significance difference in marital status between the two groups (P=0.000), while 61.4% of the sickle cell caregivers were single, 85.6% of the non-sickle cell caregivers were married.

The majority of the primary caregivers in both groups were of the Yoruba Ethnic group accounting for 97.1% and 81.4% of the sickle cell and non–sickle cell group respectively.

The majority of primary caregivers in both groups were self-employed and had monthly income which categorized them above the poverty level.

Table 2 depicts that the parental figure of SCD children had higher (worse) scores for illness intrusiveness than the non-SCD caregivers (26.17(15.8) versus 26.11(11.6); p=0.000). Table 2 also shows significant differences in the mean illness intrusiveness score among the two groups in the subscales of "marital, sexual and family relation" and "other aspects of life" with the sickle cell caregivers scoring higher than the non-sickle cell group.

Table 2. Illness intrusiveness scores of parental figures

Caregivers IIRS	Mean (SD)	p-value
1.Total IIRS		
SCD	26.2(15.8)	0.000
Non-SCD	26.1(11.6)	
2.Feelings and diet		
SCD	3.9(3.2)	0.560
Non-SCD	3.8(3.0)	
3.Work and Finances		
SCD	5.3(3.6)	0.619
Non-SCD	4.6(3.5)	
4.Recreation and social relations		
SCD	5.4(4.0)	0.093
Non-SCD	4.6(3.7)	
5.Marital, sexual and family life		
SCD	5.5(5.0)	0.020
Non-SCD	4.4(3.6)	
6.Other aspects of life		
SCD	5.11(4.625)	0.000
Non-SCD	3.26(2.407)	

In Table 2 above, although not statistically significant, the mean score for recreational and social relations is lower for the non-sickle cell group of caregivers which suggests illness intrusion into the social life and therefore, poor social life for caregiver of children living with SCD.

Table 3 below shows the quality of life scores of the children who participated in the study. There was no statistically significant difference between the two groups of children.

Despite the higher score (worse quality of life) for the total PedQoL for the Non-SCD group, it is notable that compared to the Non-SCD group the SCD group had higher(worse) quality of life with their interaction with "peers" (2.0 versus 1.3), poorer school QoL scores (4.4 versus 2.7) and poorer physical health QoL (3.1 versus 2.1).

Table 3. Quality of life (PedQoL) scores for the children

PedQoL n=70	Mean (SD)	p-value
1.Total-PedQoL		
SCD	15.6(12.9)	0.453
Non-SCD	16.4(13.2)	
2.Peers-PedQoL		
SCD	2.0(3.9)	0.305
Non-SCD	1.3(2.8)	
3.School-PedQoL		
SCD	4.4(2.7)	0.078
Non-SCD	3.9(2.9)	
4.Physical-PedQoL		
SCD	3.1(5.7)	0.196
Non-SCD	2.1(5.0)	
Feeling-PedQoL		
SCD	3.7(3.8)	0.368
Non-SCD	4.4(4.0)	

Table 4 shows that for all the participants in this study, the caregivers' illness intrusiveness correlated positively and significantly (r^S=.475; p=0.000) with the quality of life scores of the children being cared for.

The correlation between the caregiver's illness intrusiveness score and PedQoL is stronger and more significant for the SCD group (r=.610; p=0.000 versus r=.383; p=0.001), particularly for Physical health PedQoL and School PedQoL.

Table 4. Caregivers Illnesses intrusiveness and PedQoL

	Variables	Mean (S.D)	r^S	p
1	All (N=140)			
	Total IIRS	26.1(13.8)		
	Total PedQoL	15.6(13.1)	.475	0.000
2	SCD group (n=70)			
a	Total IIRS caregiver	26.2(15.8)		
b	Total PedQoL	15.6(12.9)	.610	0.000
c	Physical PedQoL	3.1(5.7)	.418	0.000
d	School PedQoL	4.4(2.7)	.376	0.018
3	Non-SCD group(n=70)			
a	Total IIRS caregiver	26.1(11.7)		
b	Total PedQoL	16.4(13.2)	.383	0.001
c	Physical PedQoL	2.1(5.0)	.317	0.007
d	School PedQoL	3.9(2.9)	.226	1.141

4. Discussion

This study has demonstrated that the majority of primary caregivers of both sickle cell and non-sickle cell children were their mothers and there is no statistically significance difference between the two groups. This may be due to the special bond that usually exists between a child and his/her mother and this may make mothers more suitable as caregivers. As pointed out by a WHO report on the importance of caregiver-child interaction for the survival and healthy development of young children, sensitivity and responsiveness are key features of caregiving behaviour related to later positive health and development outcomes.[13] Accordingly, the capacity of infants and young children to cope with biologically challenging conditions such as illness is dependent on the ability of caregivers to adjust their caregiving to the special needs of the child, which maternal figures are readily suited for.[13,14]

Research has demonstrated that mothers received significantly higher ratings for involvement in caregiving tasks than their fathers.[15] The aforementioned research also demonstrated that mothers spent significantly more time as caregivers and can be referred to as the "shock-absorbers" in the family.[15]

Findings from this study showed that a significantly higher proportion of the parental figures of sickle cell children are single (61.4%) compared to parental figures of non-SCD children, likewise, the majority of parental figures of SCD children are mothers (73.4%). These findings imply that many of the sickle-cell children's mothers are single and this calls for further research to know why they are single mothers. However, one possible explanation could be that the relationship that produced those children did not result in marriage. This could be due to the fear of further bearing sickle-cell disease children after marriage. If this explanation holds, it will be a pointer to inadequate genetic counselling in our society. It is important to educate the populace on the need to do genotype tests by intending couples before engaging in conjugal relationships. This will prevent giving birth to a child with SCD which may be a reason to terminate such relationships with the attendant proliferation of single mothers with SCD children in our society.

Various research works have demonstrated the role of pre-martial counselling in reducing the prevalence of sickle cell disease in children in Nigeria. However, this important primary preventive method seems underutilized. According to Adeyemo et al in their study on the level of awareness of genetic counselling in Lagos, while 86% of respondents knew about genetic disease, only 30.3% of individuals had been exposed to genetic counselling.[16] Although the aforementioned study was published in 2007, it can be inferred that the participation of people in premarital genetic counselling is still poor to date, considering the findings in our study.

The finding that the majority of the caregivers in both groups live above the poverty line may be because UCH is a tertiary health institution and one of the best in that category

in Nigeria which is also relatively affordable to the middle and lower social class.

On the illness intrusiveness of sickle cell disease among the primary caregivers, this research has demonstrated higher and statistically significant total and subscale mean scores among the caregivers of children with SCD compared to the non-sickle cell group. This is so in the sub-scales of "marital, sexual and family relations" and other "aspects of life". The lower IIRS in the domain of "marital, sexual and family relations" among SCD caregivers in our study reflects the finding that the sickle cell children caregivers are majorly single mothers who could not possibly enjoy good spousal relationships and sex life. Also because of the challenges of caring for the sickle cell child especially repeated crises, their caregivers' involvement in social activities and other relationships may be negatively affected. Our finding is similar to that found in a study of caregivers of children living with Prada-Willi syndrome which is another chronic paediatric disease.[17] It was reported that the unpredictability of the occurrence of the crisis and the intensity of symptoms in children with Prada-Willi syndrome resulted in parents finding themselves completely engrossed with the caregiving role with a subsequent negative impact on marital and sexual life and oftentimes parents tend to give up on any form of family relationship.[17]

The finding of a higher level of intrusiveness in the subscale on "other aspect of life" for caregivers of children with SCD is also instructive. The "other aspect of life" in the IIRS captures the "involvement in community or civic activities", "self-improvement or self-expression activities" and "religious or spiritual activities".[1,2,5] The burden of care for a child living with SCD understandably may lead to the inability to participate in community or civic activities and self-developing activities for the parental figure as found in this study. However, the negative effect of caring for a sickle cell child on the religious or spiritual activities of the parental figure is an interesting finding in this study. This is because it has been pointed out that when people are challenged by something like serious illness they frequently turn to spiritual values to help them understand or cope with their illness. [2,3,5] This tends to be the case for a parental figure who is dealing with the burden of caring for a chronically ill child but reverse is the case in this study. Plausibly, in this study the parental figures' faith regarding their spiritual and religious beliefs is intact however they are just unable to attend the activities involved.

This study corroborates research that had reported a strong positive correlation between the caregiver's illness intrusiveness and quality of life of the child being cared for particularly when the child is living with a chronic illness like sickle cell disease. It is known that caregivers of children with a chronic illness often report increased intrusion of the child's illness on many aspects of their life.[10,18,19]. Therefore, as found in this study and many others, it is not surprising that caregivers of children with SCD who have high levels of care burden have alarmingly high rates of maladjustment.[1,18,10] This study also supports the fact that family caregivers or parental figures of children living with SCD may experience a struggle for control and coherence in their lives, living a very different life compared to parents without a chronically ill child.[1,10,18]

Living with SCD has been associated with features of poor quality of life in the individuals themselves.[1,20,21] As found in this study and supported by other studies children with SCD experience more significant limitations in general physical health and functioning and more limitations in their academic functioning and attributed to their physical health.[1,9,22] It is known that the frequency of vaso-occlusive pain episodes is associated with decreases in QoL.[21,22] In children, the SCD crisis, especially the painful episode correlates with several facets of QoL including school absences and lower academic performance compared to healthy or acutely ill children as buttressed by the result of this study. [1,9,22]

5. Conclusion

In recent years, Illness Intrusiveness and Quality of Life (QoL) measurements have emerged as an important health outcome in clinical practice improvement strategies.[2,5,18,20] It is known for a fact that utilizing Illness Intrusiveness and QoL assessments in the clinical setting can facilitate physician-patient communication and identify "hidden morbidities" and psychosocial functioning deficits in individual patients that might otherwise go unidentified. Outcome of Illness intrusiveness and QoL assessments may indicate problem areas that need to be further explored and can aid attending physicians in designing appropriate treatment interventions.

It is important to address the illness intrusiveness experience of caregivers or parental figures of children, as a good adjustment to the caregiving process by the parental figure, goes a long way in improving the quality of life of the caregiver and inadvertently the prognosis of the disease, particularly for a common chronic disease like of SCD in children. Research has linked effective management of SCD to lower illness intrusiveness of the primary caregiver.

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