

Evaluation of the Challenges of Spousal Support and Care for Partners with Chronic Illnesses in a Poor Resource Setting of Akwa Ibom State, Nigeria

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Abstract

Background: The rate at which partners are facing various challenges of caring for their spouses with chronic illnesses is becoming very alarming. Non-communicable diseases (NCD) such as diabetes, cancer, respiratory diseases, kidney and cardiovascular diseases which are chronic diseases are the leading cause of death globally. Marriages faced with any of these conditions expose their spouses to a lot of challenges in their daily life. The aim of this study was to evaluate the challenges faced by spouses caring for partners with chronic illness in a poor resource setting.

Method: This was a cohort longitudinal study. A descriptive design with a qualitative approach was adopted for the study. A purposive and simple random sampling technique was used in selecting 30 thirty partners who were caring for chronically ill spouses. The target population were spouses aged 50 and above. The interview was recorded, transcribed and analyzed using qualitative content analysis.

Results: The results of the findings of the study indicated that; daily life demand, coping with the chronic illness and leisure time for the spouse were the major challenges of spouse support and care of partners with chronic illness.

Conclusion: The burden of non-communicable diseases which gradually resulted in chronic illness poses serious challenges to spouse support and care of partners with chronic illnesses in Nigeria and it is gradually increasing globally. Based on the findings of this study; daily life demand, coping with the chronic disease and partners leisure time were the major challenges faced by the partners whose spouses suffer from chronic illness.

Keywords: *Challenges; Spouses Support and Care; Chronic Illness*

Introduction

Chronic conditions are mainly physical or mental health conditions that last for more than one year [1] and are mainly caused by noncommunicable diseases such as cardiovascular diseases, cancer, respiratory diseases and diabetes [2].

The burden of non-communicable diseases is gradually increasing globally, especially in developing countries with different risk factors contributing to its surge [3]. It occurs as a result of the combination of genetic, psychological, environmental and behavioral factors [2].

It has become a global Health concern since the burden of these non-communicable diseases negatively impacts the low income countries. Non-communicable diseases killed about 41 million people each year, equivalent to 71% of all deaths globally and about fifteen million people die from NCD yearly between the ages of 30 and 69 years; 85% of these premature death occur in low and middle income countries [2].

In Nigeria, the total deaths from NCD are about a quarter of all the total deaths yearly [4].

Whenever someone is diagnosed with a chronic illness, considerable number of devastating consequences follows. Patients with chronic illnesses with high symptoms burden affects not only the patient, but also the entire family. To maintain a normal life, partners with chronically ill spouses are often involved in the spouse's daily activities and the ability of the partners to cope with the situation is stressful [5]. Partners caring for chronically ill spouse face a lot of challenges in their daily life. Their needs are always overlooked despite the fact that they have limited time for themselves and these have negative effects on their physical, psychological, social and economic wellbeing.

Physically, the spouse everyday life is completely taken off at the expense of his/her health because of the difficult task which needs a lot of effort and energy to do in caring for the ill partner. Psychologically, there is that emotional loneliness, the spouse having the feeling of being detached from the partner because that leisure time and intimacy in their relationship is no longer strong.

Socially the spouse may be completely cut off from his or her social life as there is limited time for themselves because of daily demand of their partners. The spouses may also face financial difficulties as the illness might have taken a lot of their resources, business may crumbled due to lack of time and attention.

In Akwa Ibom State, despite the fact that the number of people suffering from these chronic illnesses is gradually increasing daily; the severity of the consequences of these illnesses and the fact that chronic illness requires spouse support and care for their partners during this period have not been thoroughly evaluated.

Very little information is known about the challenges faced by the spouse whose partners are chronically ill. Furthermore, there is a paucity of research on the effects of chronic illnesses on their spouses support and care especially in a poor resource setting as we have in Akwa Ibom State.

It is against this back drop that this study seeks to evaluate how chronic illness of spouse affects partners daily life demand, how a spouse cope with partner's chronic illness and also how it affects their leisure time. The study will also fill in the gap of knowledge by enlightening and preparing the mind of couples of possible challenges of chronic illness in a family.

Methodology

Study design: This study was a hospital based longitudinal study among patients that have been diagnosed of these diseases (hypertension with complication - stroke, diabetic foot ulcer, chronic obstructive airway disease, chronic kidney disease and cancer advanced stage), who have been coming to the hospital regularly for medical checkup for the past one to two years.

Research area

The study was carried out in the University of Uyo teaching hospital, Uyo which is located in the Uyo metropolis. This centre was chosen because it is a referral center where all severe and complicated diseases are referred to for proper treatment and rehabilitation; it is also a centre for research.

Population of study

The population of study were all spouses whose partners were chronically ill and visited the hospital during the period of research (from 2018 - 2021) and were also willing to take part in the research.

Sampling and sampling technique

Purposive sampling and simple random sampling technique were adopted for the study where fifty (50) spouses of chronically ill patients were selected for the study.

Data collection technique

The tools for the study were in-depth interview and observation. The interview was conducted using an interview guide that was grouped into four sections. The sections included the socio-demographic data, chronic illness of spouse and daily life demand, coping with spouse chronic illness and spouse illness and partner's leisure time. The interview was conducted using a face-to-face method with the respondents.

Sitting in a conducive environment for both privacy and confidentiality. The interview guide was used to guide the researcher on areas to ask questions.

Data collection

Primary data which comprised of firsthand information and data were considered and used for the study. They were obtained by the researcher in the course of the field survey, using a combination of a detailed interview and observation instruments.

Method of data analysis

Descriptive and qualitative approaches were adopted for the study. The data were analyzed using thematic analysis, frequency tables and percentage distribution.

Consent to participate

Informed written consent was taken from study participants. Information obtained was treated with high level of confidentiality as personal identifiers were not used in the study. Ethical consideration was given high priority in all aspects of the research.

Results

Frequency and percentage distribution of the socio-demographic characteristics of spouse who support and care for partners with chronic illness

Majority of the respondents (61; 34%) were between the ages of 61 and above and they were all married still living together. Similarly, majority (23; 46%) had secondary school education which revealed that they were all literate and were mostly Christians (38; 78%). Those who were married for between 26 - 30 years topped the list (14; 28%). Majority of them were self-employed (17; 34%). Almost all of them (42; 84%) were from Akwa Ibom state. Greater no of them (22; 44%) were those who earned between 20 - 50,000 Naira per month while some said they don't know since there was no documentation to that effect.

Variables	Frequency (Uyo)	Percentage (%) (Uyo)
Age		
20 - 30	2	4
31 - 40	6	12
41 - 50	12	24
51 - 60	13	26
61 and above	17	34
Total	50	100

Marital status		
Single	-	-
Married	50	100
Widow	-	-
Divorce/Separated	-	-
Total	50	100
Educational level		
Primary	17	34
Secondary	23	46
Tertiary	8	16
No Formal Education	2	4
Total	50	100
Religion		
Christian	38	76
Muslim	8	16
Traditional	-	-
None at all	4	8
Total	50	100
Years of marriage		
10 – 15	4	8
16 – 20	8	16
21 – 25	12	24
26 – 30	14	28
31 – 40	12	24
Total	50	100
Occupation		
Self Employed	17	34
Petty Traders	11	22
Civil Servant	16	32
Retires	6	12
Total	50	100
State of origin		
Akwa Ibom State	42	84

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Other States	8	16
Foreigner	-	-
Total	50	100
Income per month		
I Don't Know	18	36
20 - 50	22	44
51 - 100	5	10
101 - 200	2	4
200 and above	3	6
Total	50	100

Table: Source: Fieldwork (2019).

Respondents view on daily life demand and chronic illness

One of the major challenges faced by spouses whose partner had chronic illness was the effect of the illness on their daily life demand especially that they have limited time left for them to attend to themselves and their businesses. Majority of the respondents complained that their spouses illness had really affected their daily life demand for example, Mrs Udoh a 55years old Woman, a petty trader married for 30 years said "I don't know what to say again, my husband had stroke, cannot use one side of his body. I am the one doing everything for him and before I could finish to attend to myself and my small business. It is not the same again all our money is gone. I Need real help".

Mr Akpan 62 year old man, a retiree, married for 28 years said 'I feel very bad about this type of sickness. The small business I started after my retirement is going down, no time for myself, my business or any other thing, my money is gone. God please help me".

The responses above pointed out that their spouses illnesses had affected them seriously. Their daily life demand had changed completely and the only hope is that one day, they will get back to normal again.

Coping with spouse chronic illness

How to Cope with the spouse sickness was another challenge of the respondents. Most of them tried and adjusted to the situation they found themselves though it wasn't easy for them.

Mrs Udofia a 57year old woman, a civil servant, married for 22 years had these to say "I have no other option than to adjust, it is really affecting me physically, emotionally, psychologically and economically. I can't sleep, no rest but I have to accept whatever situation I found myself. Even I can't pray anymore".

Narratives above indicated that it was not easy for the spouses to adjust to the unusual demand of the illness. Dealing with the difficulties and worries about the future outcome, was accepted by faith. All their pattern of life including, rest, sleep, religious activities etc. were all adjusted. The expenses were far more than what they expected. It weighs them down causing severe fatigue, trauma, disrupt the daily life of couples and family. It results in reworking of family relationship.

Spouse illness and partner's leisure time

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Another aspect of challenge was in the area of leisure time. Almost all the respondents said they can't even remember this aspect of their lives anymore. For example, Mr Effiong a 66year old man married for 30 years said "Ah at my age, with my wife condition, no more social life. I can't even visit friends, no religious activities again".

Mrs Nduke a 57year old civil servant, married for 27 years said, "no more social meetings or club for her again, no relaxation, only few friends come visiting".

Responses from the respondents above showed that due to their state of mind concerning the spouses condition, social life has become a history, religious activities are limited, and only very few friends visit them. Therefore, instead of focusing on what they cannot do, they only stay around their spouses to reassure them of their love for them which was more comforting at these times.

Discussion

Daily life demand of spouse whose partner has chronic illness was a major challenge. The results of the study revealed that chronic illness really affected their daily life demand in all aspects. They all requested for assistance to help care for their spouses and also pray for their spouses to be up and about again. This assertion is in support of the view by Erickson, *et al.* who in the findings of their study on experiences of partners living with person with chronic illness indicated that their experiences of support from formal care providers varies [5]. They expressed need for more assistance and also concluded that, in handling daily life, the partners balanced demands and resources to identify possibilities to move forward and find meaning in life. Similarly, this study was also in agreement with Ray (2006) who found out in his study that partners in long- term marriage, find it natural to provide informal care for their ill spouse [6]. Partners in a happy marriage emphasized love and affection as motivation for providing care, whereas those in unhappy relationship emphasized duty and obligation.

He concluded that although it may be considered natural to assist one's ailing spouse, providing care affects the care giving partner in different ways. Likewise, Luttik, *et al.* (2009) in their study on quality of life in partners of people with congested heart failure; gender and involvement in care also arrived at the same conclusion that in providing care, it affects the caregiving partners in different ways [7]. These include limited time for own interest, negative effects on social life, reduced quality of life and

experience of psychological distress. The study also confirmed the result of the work carried out by Sanders and Power (2009) on the roles, responsibilities and relationship among older husbands caring for wives with progressive dementia and other chronic conditions [8]. It noted that patients with chronic illness with high symptoms burden affects not only the patients but also the entire family. To maintain a normal life, partners with a chronically ill spouse are often involved in the spouse's daily activities and the situation is stressful. Whereas, Vogt (2022) argued that a long or severe illness is usually a crisis - turning point that lead to ruin or renewal [9]. A chronic or life threatening illness create a demand for a new intimacy, not only family daily pattern change, but also the expectations of how you will live, love and share in mutual life. She added that going back to the way things were is the only way going forward. An article in Science Daily (2019) pointed out what people said in their wedding vows, many of them promised to stand by one another in sickness and in health [10]. But, a new study suggests that as married couples aged and develop chronic conditions, the daily demand of coping with their own health demands and those of their spouse may take a mental toll on them. When husbands and wives, both have chronic health conditions and needed different kinds of selfcare from their partners, husbands fared worse. Their depression symptoms were significantly higher, but these effects were not found in wives. The study by Vogt (2022) also agreed with this finding that in managing chronic illness of spouse, the care-giver might have to do things that he or she had previously not done [9]. The illness can become the focus of your life and everything can revolve around it; researching it, getting to/from treatment, dealing with side effect, doctor's visits and support groups. Even cooking can be a challenge if the ill person needs a special diet or needs to be coarse to eat. Recreational pursuits that they both previously enjoyed may become physically impossible. Travelling may be more difficult, but this does not mean that you don't have fun. You just have to be creative about finding new interest that fits changing physical abilities.

Coping with spouse chronic illness was another challenging experience of the spouses. Lazarus and Folkman (1984) described coping as a personal ability to manage stressful situations which can be divided into two groups [11]. The challenges were both problem- focused coping and emotional - focused coping. The study indicated that it was not easy adjusting to unusual demand of illness especially dealing with difficulties and worried about the future. This is in line with the study by Riazuelo (2021) who in this paper examined couples psychological experience when one of them

suffers from a chronic disease [12]. The results indicated that spouses complained of being weighed down because of the sickness causing severe fatigue and becoming traumatic.

Badr and Carmack Taylor (2008) maintained that in coping with spouse chronic illness better, only couples who knew they are going through this as a team will be less stressed and worried [13]. They added that keeping married relationship strong can help better cope with the chronic disease situation. The findings also confirmed what Sanders and Power (2009) observed in their study that patients with chronic illness with high symptoms burdens affect not only the patient but also the entire family [8]. To maintain a normal life, partners with a chronically ill spouse are often involved in the spouse's daily activities and the partner's ability to cope with the situation is stressed. Similarly, Bruno (2012) agreed that having a chronic illness, the strain may push both peoples understanding off "in sickness and in health" to its breaking point. If the spouses involved are young and spouses who are caregivers are six times more likely to be depressed than spouses who do not need to be caregivers [14].

Another major theme of the study was how the spouse's illness affects their leisure time. The findings of the study was that they can't even remember these aspects of their lives anymore due to spouse's illness, no more social life, relaxation or visitation.

These findings are in line with Bruno (2012) who argued that chronic illness can be isolating [14]. Having a strong relationship is a buffer against depression but with chronic illness you or your partner may not be able to visit people's homes, if for instance, one person uses wheelchair or one might be afraid of being rejected especially if condition causes twitching or problem with bladder control. It can even make either of the partners to be easily tired, making difficult to plan and follow through on social engagements, therefore affecting their leisure time negatively. Similarly, Manne and Badr (2018) also supported these findings that it can be difficult to adapt to a spouse's chronic illness, sometimes the condition calls for changes to life plans for the future, at times change to your everyday lives including your leisure time, such as watching football matches, going out with friends [15]. Also, in a study by Ian (1996) who aimed to establish if frequent participation in leisure activities helped widow or widowers adapt to widowhood and to maintain lower stress levels, the results showed that leisure activities most frequently participated by widows or widowers were found to be home based activities with family or friends [16]. Greater participation in leisure activities was found to be negatively correlated with stress

scores, suggesting an association between participation and stress reduction for recently bereaved widows and widowers [17].

Conclusion

The burden of non-communicable diseases which gradually resulted in chronic illnesses poses a lot of challenges to spouses and it is gradually on the increase globally based on the findings of this study. Daily life demand, coping with spouse chronic illness and partner's leisure time were the major challenges faced by the partners whose spouses suffer from chronic illnesses. It was therefore recommended that during marriage counseling to the intended couple, emphasis should include what they should expect during their old age and also should be prepared psychologically and emotionally on how to deal with it. The Government in Akwa Ibom state and Nigeria as a whole should make it mandatory for the National Health Insurance Scheme (NHIS) to engage the elderly people too and not only care for their workers alone in order to reduce the financial burden to some extent.

As a form of recreational therapy spouses and their partners should be well informed about the issues they are facing and how to handle it because ignorance on its own can also add to the challenges of the spouses.

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