

Schizophrenia: its psychological effects on family caregivers

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Abstract

Purpose: Caregivers of patients diagnosed with schizophrenia experience moderate to severe caregiver burden and are at risk for developing mental disorders. This study explores the psychological effects and coping strategies of family caregivers of relatives diagnosed with schizophrenia in the developing world.

Methods: This qualitative study used the register of a community mental health clinic at a Jamaican hospital to purposively select and recruit five primary family caregivers of clients diagnosed with schizophrenia (based on the DSM IV). Consenting participants were interviewed using a semi-structured interview guide. Data were analyzed using thematic content analysis.

Results: Four of the five caregivers studied were females. Participants were either parents (4) or siblings (1) of the client diagnosed with schizophrenia and aged 42 -57years. Participants experienced feelings of anger, sadness, loss of libido, loss of appetite and depression. They expressed feelings of fear, guilt, stigma and stress related to financial responsibilities in caring for their relatives. Coping mechanisms included social support from family members and their strong faith in God.

Conclusion: Participants reported experiencing major psychological distress and ineffective coping. Community based management of individuals with schizophrenia should include strategies to support family caregivers.

Keywords: Family Caregiver; Schizophrenia; Psychological Distress; Burden of Care.

1. Introduction

Schizophrenia is a mental disorder characterized by delusions, hallucinations, disorganized speech and behaviour (Tandon et al. 2013). The disease affects mainly persons 15-35 years, and symptoms may cause social or occupational dysfunction. The global prevalence of schizophrenia is estimated at 1.1% of the population over the age of 18 years (WHO 2011). In the United States, there are roughly 87,000 acute-care admissions for the treatment of schizophrenia annually (Marcus & Olfson 2008), while in Taiwan, there are 76, 458 people with schizophrenia inclusive of admissions and outpatients (Huang et al. 2009). While there is a lack of reliable data on the epidemiology of schizophrenia in the Caribbean, it is estimated that at least 20 million persons diagnosed with schizophrenia, live in developing countries (Caribbean Community [CARICOM] Secretariat 2007).

The treatment of mentally ill patients has improved vastly with atypical antipsychotics and the provision of community care and rehabilitation (Huang et al. 2008). It is estimated that 50%- 90% of patients with chronic schizophrenia now live at home (Awad & Voruganti 2008). This is reflective of policy changes advocating for the deinstitutionalization of clients diagnosed with schizophrenia to live in the community with their families (Huang et al. 2008).

Caring for relatives with schizophrenia may result in a significant burden to caregivers (Chan 2011). It is estimated that as high as 90% of caregivers experience moderate to severe burden, and among caregivers of patients diagnosed with schizophrenia are a

potential high-risk group for mental disorders (Magliano et al. 2005, Koujalgi & Patil 2013, Lasebikan & Ayinde 2013). Caring for a relative with schizophrenia has been ranked a greater burden than that associated with caring for patients diagnosed with dementia (Nauert 2011). Thus, they require comprehensive intervention in order to reduce the growing incidence of chronic enduring diseases, including mental disorders. Reportedly, family caregivers are confronted with fear and anxiety related to the patient's symptoms and the cost of treatment at home (Awad & Voruganti 2008, Panayiotopoulos et al. 2013). Additionally, family caregivers may experience high levels of psychological, physical, social and financial strain resulting in depressive symptoms, self-blame and substance abuse (Nauert 2011, WHO 2011).

According to Lasebikan and Ayinde (2013), caregivers' burden has two dimensions. The first burden is "objective burden" (effects on the household, including financial loss, effects on health, on children, and family routine; and the abnormal behaviours shown by the patient) and "subjective burden" (the extent to which relatives feel that they carry a burden). Interventions to support family caregivers are necessary if the quality of home-based care for individuals living with schizophrenia is to improve (Zahid & Ohaeri 2010). Lauriello Lauriello and Pallanti (2012) suggested that family space needed members who participate in family psychoeducational programs experience lower levels of subjective burden, improved life satisfaction and acquire greater knowledge, hope and empowerment. Interventions should be patient-oriented and facilitated by trained personnel (Veltro et al. 2006). Here patients are taught how to recognize events and situations that may

be highly stressful, highlighting early-warning signs of stress overload and impending recurrences.

Despite numerous studies addressing the difficulties experienced by family caregivers globally (Li et al. 2007, Awad & Voruganti 2008, Chan 2011), this issue has not been well studied in the Caribbean. Furthermore, a review of 68 journal articles on the support offered to caregivers of clients with schizophrenia (1980-2008) highlighted the need for research from developing countries and an assessment of the economic impact of caregivers support interventions (Macleod et al. 2011). Macleod et al. (2011) also bemoaned the fact that less than half of the studies reviewed included demonstrated the inclusion of nurses.

Jamaica estimates costs of US\$600 million per year for depressive and schizophrenic illnesses (CARICOM Secretariat 2007). The 2008 Community Mental Health register (Ministry of Health Jamaica, 2008) suggested there were over 27,000 persons with psychotic disorders of which more than a half were diagnosed with schizophrenia. There is a clear need for nurse generated empirical evidence regarding the needs of caregivers of clients diagnosed with schizophrenia residing in developing countries such as Jamaica.

In this study the psychological effects of caring for relatives diagnosed with schizophrenia are explored and a description of the coping strategies utilized by family caregivers for clients attending a community mental health clinic at an urban hospital in Kingston, Jamaica is provided.

1.1. Theoretical frame work

The Caregiver Stress Process Model by Pearlin et al. (1990) provided a theoretical framework for this study. The theory assumes that most families are committed to caring for their relatives with mental illnesses at home, which is potentially a fertile ground for persistent stress. This model has provided guidance for understanding caregiver stress across varying populations (Ice et al. 2012). The Conceptual Components of Caregiver Stress Process described by Pearlin et al. (1990) include four domains. The domains are the background and context of stress, the stressors, the mediators of stress, and the outcomes or manifestations of stress. Stressors may be primary and secondary and are typically the conditions, experiences, and activities that persons may find problematic. These stressors cause a threat to the individual by impeding their efforts and defeating their dreams. Primary stressors stem directly from the needs of the patient while secondary stressors involve role strains, which are found in roles and activities outside the care-giving situation. These strains are appraised by three indicators: reductions in household income, increases in expenditures related to the care and treatment of the patient, and whether there is enough money to make ends meet month to month. Past research has indicated that under conditions of enduring hardships, self-concepts may be damaged (Pearlin et al. 1990) and when this happens, people are more likely to suffer symptoms of depression. Care giving to chronically disabled relatives fits this scenario. Dimensions of self-concept include role captivity in which the care giver feels trapped by relative's illness and the loss of self.

1.2. Mediating conditions and Outcomes

Coping, which involves management of the situation giving rise to stress and social support are generally regarded as the two principal mediators. Social support may prevent or inhibit the development of secondary stressors. Coping/supportive factors construct include social support [relationships with extended family, friends and neighbours], family function (the extent to which a family works as a unit) and stress management [the number of strategies and practices of the caregiver in response to problematic situations] (Du Preez 2010). Pearlin et al. (1990) suggest caregiver stress may generate effects or outcomes relating to the well-being, physical and mental health, and their ability to sustain themselves in their social roles. Schulz and Sherwood (2008), concurred that

caregiving has all the features of a chronic stress experience; it creates physical and psychological strain over extended periods of time. Documented mental health indicators include standard symptom measures of depression, anxiety, irascibility, and cognitive disruptions (Pearlin et al. 1990).

1.3. Epistemology

This study was conducted in partial fulfilment of a Masters in Nursing, and the researchers were not employed at the institution at which the study was conducted. The project was supervised by registered nurses trained at the masters and PhD levels. Prior to entering the postgraduate program the researcher worked as a mental health officer. This topic was selected based on personal experience and observations of caregivers of clients with mental illnesses and the absence of formal support systems within the Jamaican healthcare system. The work was motivated by the need to objectively elucidate the plight of caregivers of the clients with schizophrenia. Though controversial, bracketing was used to ensure the single female data collector remained reflective; consciously suspending personal opinions and prejudices (LeVasseur, 2003). The researchers acknowledged limitations associated with being a novice researcher and consciously embarked on a simple descriptive study which committed to studying the client's experience caring for relatives diagnosed with schizophrenia in the natural state; providing insight from the developing world. Furthermore, interpretations will be based on general consensus among researchers and low levels of inference (Sandelowski 2000, Dowling & Cooney 2012).

2. Methodology

2.1. Research design

A descriptive qualitative research design, based on phenomenology was used to collect data on the psychological effects of caring for clients diagnosed with schizophrenia. Qualitative methods are effective in bringing to the front the experiences and perceptions of individuals from their own perspectives (Polit and Beck 2013). The Consolidated Criteria for Reporting Qualitative Research (COREQ) was used to guide this study.

2.2. Population and setting

The target population consisted of one hundred primary family caregivers who accompanied clients on monthly clinic visits to a community mental health clinic attached to a Type A hospital. Type A hospitals provide comprehensive secondary and tertiary health-care services and are referral centers for hospitals both in the public and private health care systems. Psychiatric clinics are held at the institution three times per week and accommodate approximately 20 patients with schizophrenia per clinic session.

2.3. Sample size and sampling strategy

Adult family caregivers of a relative diagnosed with schizophrenia based on the Diagnostic and Statistical Manual of mental disorders, fourth edition (DSM IV- TR) and who attended the Community Mental Health clinic at that urban hospital were eligible for the study. Caregivers of clients who had been diagnosed for a period of one to two years were selected based on the topic of interest. The sample size in a qualitative study is typically small often ranging from five to twenty units of analysis (Polit and Beck 2013). Therefore, ten family caregivers were contacted by telephone and through purposive sampling; five were recruited into the study.

2.4. Gaining entry and ethical considerations

Approval to conduct the study was granted by the required institutional review boards. Permission to conduct study was granted by the Chief Executive Officer and the Director of Nursing Services. Staff members at the clinic were advised of the proposed study and their assistance was sought to identify prospective participants using the clinic register. Participants were accessed through a review of clinic records to identify clients diagnosed with schizophrenia and provision of telephone numbers by the health professional. This method was used to protect the privacy of the client. The study was explained to potential participants via telephone. Participants who agreed to participate were given an appointment to be interviewed on the designated day of the relatives' monthly clinic appointment.

Written informed consent was sought from participants with specific reference to the use of an audio-tape to record the interviews. Privacy was maintained with only client and interviewer present during all the interviews; which were conducted in a small quiet secluded room at the institution.

2.5. Data collection procedures and measures

Data were gathered using a modified semi-structured Zarit Burden Interview Schedule consisting of twenty two (22) open-ended questions and a socio demographic data sheet consisting of 13 closed-ended questions. The Zarit Burden Questionnaire has been used to measure the caregivers' perceived burden of providing family care (Seng et al. 2010). This semi-structured interview guide facilitated the discussions with family caregivers and allowed them to share their feelings and experiences in caring for a relative with schizophrenia. Although the Zarit Burden questionnaire has been widely used to measure caregiver burden in quantitative studies (Seng et al. 2010), there is evidence to support its use as an appropriate framework for qualitative studies (Gort et al. 2003) which also adds credibility to the body of work (Shenton 2004). All of the interviews were audio-taped, and none exceeded an hour in duration. Any variation in the duration of the interviews was dependent on the achievement of data saturation. A maximum of two interviews were completed on each clinic day. This saw the completion of data collection over a period of one week.

2.6. Establishing trustworthiness for results

The interview guide was pre-tested using five caregivers outside of the study institution to ensure face validity and this consultative process allowed for the input of three mental health experts who were familiar with the study topic. Although a neophyte researcher an overt effort was made to remain in a state of epoche by the data researcher. Probing and iterative questioning assisted the researcher to clarify interviewees' experiences where necessary and field notes were used to enhance trustworthiness and objectivity of the process (Shenton 2004). Interviews were summarized for member checking at the end of each interview and participants asked to clarify where necessary as the researcher actively sought feedback.

2.7. Data analysis

The tape-recorded interviews were reviewed twice for gaining insight and then transcribed verbatim. The transcript was checked for accuracy and identifying data were replaced with pseudonyms. Data coding was done manually by working systematically to assign categories as described by Huang et al (2009). The categories used to develop themes were selected on the basis of repeated patterns across the data set (Braun & Clarke 2006). Thematic Content Analysis (TCA) was then used to summarize key features of a larger body of data. Themes were clearly defined, placed in clusters and given working titles (Braun & Clarke 2006). Three major themes emerged from this study: the burdens of caring, emotional

burdens and strategies of coping. Finally, specific quotes were identified to illustrate these themes. TCA is the most foundational of qualitative analytic procedures and in some way informs all qualitative methods (Anderson 2007). The data analysis process was subjected to peer scrutiny as the research team included two academic supervisors (Shenton 2004).

3. Results

3.1. Demographic characteristics of the caregivers and relatives diagnosed with schizophrenia

The demography of the family caregivers of clients with schizophrenia was described in order to facilitate contextualized interpretation of the transcript. Information about the relatively homogenous sample of caregivers' age, gender and education were noted and tabulated (Table 1). Four of the caregivers were females whose ages ranged between 42 and 48 years while the fifth participant was a 57year old male. Family members of the clients were parents (4) and siblings (1). Almost all of the caregivers were employed, affiliated to a church and had limited social support. Table 1 also shows that the respective clients with schizophrenia were between the ages of 15 and 32 years of which three were males, and two were females. The average duration of illness was approximately one year and eight months.

Table 3.1: Demographic Characteristics of Family Caregivers and Respective Family Member who has Been Diagnosed with Schizophrenia.

Care Giver	1	2	3	4	5
Sex	female	Female	male	Female	female
Age	43yrs	48yrs	57yrs	42yrs	46yrs
Marital status	Divorced	Married	Single	Single	Single
Education	Tertiary	Secondary	Primary	Secondary	Tertiary
Support Group	No	No	No	No	No
Social Support	Yes	Yes	Yes	Yes	Yes
Relationship to client	Brother	Son	Son	Daughter	Daughter
Client's gender	Male	Male	Male	Female	Female
Client's age	32 years	24years	15years	15years	17years
Duration of client's illness	2 years	2 years	2 years	1year	2 years

The findings of the study are presented based on the three major themes which emerged from the in-depth interviews conducted: (a) Burdens of Caring (b) Emotional Burdens and (c) Strategies of Coping.

3.2. Burdens of caring (theme 1)

Caregivers described the needs of the patient and the nature and magnitude of the care demanded to adequately meet the needs of the client. Almost all the family caregivers stated that their relatives were dependent on them for preparing meals, purchasing medication and food, and washing clothes among other activities. Some participants said that their relative was dependent on them meeting hygienic needs; this was exemplified by the following quotes:

'...sometimes I have to tell him to go to the bathroom, tell him to brush his teeth, comb his hair, his shoe is dirty his shoes need to clean' (mother, age 48).

'...sometimes I have to tell her when to change her sanitary pad, to floss and brush her teeth' (mother, age 42). These responsibilities appeared to be burdensome on the family caregivers as they made statements such as:

'... I have to take care of my son; you understand and his illness is taking a toll on me' '...sometimes I feel like I just can't manage, I have to keep pushing myself' (sister, age 43, tertiary education). Yet another, reflected: '...sometimes I feel overwhelmed, and I wonder if one day it will change' (mother, age 46, tertiary education).

3.3. Emotional burdens (theme 2)

Caregivers described the range of emotions they experienced while caring for their relatives with schizophrenia. The emotional burdens were characterized by feelings of anger, sadness, fear and depression. For example, caregivers expressed feelings of anger and frustration when the client diagnosed with schizophrenia displayed aggressive behaviour (one care giver was reportedly hit in the head), or when there was no other family member to assist in caring for the relative. Some caregivers expressed sadness and blamed themselves because they felt that their relative's illness came about because of their actions. One participant suggested that perhaps she did not give the relative enough attention:

....'sometimes I feel sad; now that he's blaming me, sometimes I feel that I did not give him any attention' (mother, age 48 years).

Fear and sadness were also expressed by the caregivers when they reflected on how the illness had changed their relative's behavior in comparison to when they were well. One of the participants stated '...I'm really scared for my life, my son's life and my mother's life even his life because at one time he wanted to jump from the balcony and we had to hold him...' (Sister, age 43 years). Almost all of the caregivers expressed feelings of depression (resulting in them 'breaking down' and crying, having sleep difficulties or decreased appetite and libido) in their daily care of the relative with schizophrenia. Some emotional burdens were reflected in the following statements made by the caregivers:

'...I don't even have appetite for sex, because is like all my cares turn to him; sometime I don't even remember that my husband is in the bed' (mother, age 48 years).

'...I feel depressed very much, because when I sit down and look on my brother the way he is now, it's heart-rending'... (Sister, 43 years).

'...I couldn't eat, cook or anything because of her illness. I have to take something for sleep...' (Mother, age 46 years).

Another participant expressed anger and explained...at times I'm angry, I even stopped speaking to him.' (Father, 57 years).

3.4. Strategies of coping (theme 3)

Caregivers described changes they made to lessen negative effects or make care giving easier. Relaxation, relying on their faith in God and support from friends and relatives were the chief coping strategies employed by study participants. Stress-relief activities reported in this study are typified by the following quotes:

...'Sometimes I bathe, watch a movie and relax and me and my husband talk about the illness' (mother age 42 years).

'I think positive, I listen to good music and I read a lot and I do fun stuff on the internet' (mother age 46 years).

'I try to pamper myself more; first time I used to just brush my teeth and go to my bed but now I take time to lotion myself more and buy a face cream' (mother, age 48 years).

Others depended on their faith and accessed social support. They reported: 'I put my trust in God, if it wasn't God I don't know how I would manage' (father, age 57 years).

'I have a prayer band; I'll go to the prayer band and tell them my problem and they will pray together'... (Mother, age 42 years).

One participant had no form of activity to make care giving easier: '...I don't even know how I manage to take care of myself; because with the stress and everything I rarely have time to really sit down and even think about myself, rarely have time; sometimes I'm really sorry for myself you know' (sister, age 43 years).

4. Discussion

The purpose of this study was to explore the psychological effects and coping strategies of family caregivers of clients diagnosed with schizophrenia. The findings revealed that the family caregivers of relatives with schizophrenia underwent major psychological distress. This was consistent with the findings of similar studies that confirmed that family caregivers experienced substantial stress and burden related to care giving (Awad & Voruganti 2008, GJI et al. 2009, Yusuf et al. 2009, Mizuno et al. 2013). The literature suggests that a chronic illness of a family member can result in strain for the caregiver due to the difficult tasks of constantly caring for another person (Brady & McCain 2004, Ganguly et al. 2010). Furthermore, this level of responsibility was likely to affect both the physical and mental health of the caregiver.

Majority of the caregivers in this study were females with an average age of 45 years who appeared to have experienced major psychological distress. It is estimated that globally, about 80% of caregivers were female; it has also been reported that the caregiver role has traditionally been entrusted to females (Mizuno et al. 2013). National Alliance for Caregiving and American Association of Retired Persons (2012), also reported that in the United States, there are far more female than male caregivers and that the average age of a caregiver is 48 years old. Women bear the greater care giving burden as mothers, daughters, wives, sisters, and friends and spend fifty 50% more time providing care when compared to male caregivers (Suthers 2006).

The Jamaican culture is also heavily female-dominated with far more single-parent homes being headed by women, who are often the ones who care for sick relatives (Bowen-Wright 2005). This latter researcher posited that some of the most competent, caring and loving caregivers were non-professionals and were mostly women. She added that the way in which they performed their duties to the patient, often leaves one to understand why caregivers suffer 'burnout' which may result in feelings of fatigue, depression, low energy levels and wanting a break from their duties. The result is abject neglect of their state of health and wellness (Bowen-Wright 2005). The women studied were the chief caregivers to their families, had jobs outside of their homes and the added responsibility of caring for the patient with schizophrenia. This was a significant burden of care to the caregiver because of the nature and magnitude of the care demanded to adequately meet the needs of the patients.

Due to the 'burden of care' in their care giving processes, caregivers experienced anxiety, fear, sadness, sleeplessness, loss of appetite, loss of libido and depression. Similar observations were made in other studies done on family caregivers (American Psychiatric Association 2014, Oshodi et al. 2012). Depression, anxiety, irascibility, and cognitive disruptions were outcomes of the caregiver stress process (Pearlin et al. 1990). The caregivers studied thought that in addition to their other duties, taking care of their relative with schizophrenia was overwhelming. According to Oyebode (2003), the needs of caregivers should be taken into account, given the high levels of stress and depression reported and intervention or support provided. The author also suggested that in some instances of extreme emotional burdens, caregivers themselves became ill due to poor coping skills. If structured support services are absent, health workers may find themselves with two patients to support where previously there was only one, supported by a caregiver (Oyebode 2003, Smith & Segal 2012).

Some caregivers in this study tried to cope with stressors by relaxation techniques such as watching a movie, putting their faith in God or seeking social support from their family members or church group. Despite these, most caregivers reported feelings of anger, sadness, fear and depression. This implied that the degree and quality of social support that caregivers received was very important in helping them to manage their stressful care giving activities, and ultimately prevent or reduce the threat of negative psychological symptoms (Smith & Segal 2012). The National Alliance for Caregiving (2010) recommend the formation of care-

giver support groups at each major health facility where caregivers can share feelings of isolation and frustrations. Family support groups provided an organization of persons who shared common care giving problems facilitating empathetic connections (Reay-Young 2001). Meeting others with shared experiences can help to reduce feelings of isolation and fear and provide an invaluable avenue for the relatives of people with schizophrenia to share advice, and information (Smith & Segal 2012). It is therefore, highly likely that caregivers would benefit from professional, comprehensive interventions.

Macleod et al. (2011) suggested that Behavioural Family Therapy (BFT) which entails structured problem solving and communication training and education sessions about schizophrenia can be beneficial to all family members involved in care giving. In addition, Comprehensive Assertive Community Treatment Outreach Programs were useful in assisting caregivers and relatives with schizophrenia (Macleod et al. 2011). A systematic review of 53 randomized controlled trials concluded that family interventions decreased the frequency of patient relapse, reduced hospital admissions (Pharoah et al. 2010). The positive outcomes were attributed to psychosocial family interventions which enhanced the capacity of relatives to solve problems and reduced levels of expressed emotion, stress, family burden. Moreover, mutual support groups involving family caregivers and patients in Hong Kong have proven an effective family intervention for caregivers of clients with schizophrenia and have improved caregiver and patient functioning (Chien et al. 2005). Mutual support groups were deemed more effective than psycho-education and standard care groups.

5. Limitations

While this study has generated valuable information, it is recommended that further studies using larger samples be conducted on caregiver experiences in caring for a relative with schizophrenia to better understand the experiences of family care givers; especially, in the long term.

6. Conclusion

The family caregivers of relatives with schizophrenia attending clinics at the institution studied were mainly females who had significant other family responsibilities and experienced major psychological distress such as anxiety, fear, sadness, sleeplessness, loss of appetite, loss of libido and depression among other symptoms. Comprehensive management of clients with schizophrenia should include structured family interventions to help caregivers maintain optimum health. It is recommended that further studies be conducted on caregiver experiences in caring for a relative with schizophrenia, with a view of policy development and implementation.

This study indicated significant distress among the caregivers. These individuals should be evaluated for psychological health and their coping mechanisms examined to determine the interventions needed. Primary prevention among new caregivers may prove beneficial to both client and caregiver.

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