

# Attitudes and Subjective Views of Caregivers of Persons Living with Schizophrenia in Harare

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**Abstract:** Schizophrenia is one of the most serious – and often one of the most disabling- types of mental illness. It is believed that about 1 % of the world’s adult population suffers from it. As a result of its severity, mental health institutions are a frequent stop for many schizophrenic patients. It is chronic, complex and challenging psychiatric disorder that needs close monitoring. There are diverse cultural beliefs, etiologies, interventions are based on caregiver perceptions based on cultural beliefs. Most relapses are triggered by caregiver negligence due to lack of knowledge. Because of the severe disabling effect on the ill person, schizophrenia renders the victim totally dependent on the caregiver. And this study looks at the perceptions and attitudes of caregivers, who are the main players of the upkeep of these patients. The study looks at emotional burden of the caregiver, and the possible ways of empowering them. The researcher used a qualitative research methodology to explore the emotional caregivers’ perceptions and appraisals of schizophrenia. It was noted that caregivers of schizophrenia are emotionally wounded, and often poorly informed about the illness. The research recommends the bi-focal intervention approach, which recommends the inclusion of the caregiver in the treatment plan. The study also recommends government assistance to the caregivers and or family of schizophrenic persons

**Key Word:** Caregivers, Cultural beliefs, patients, schizophrenia

## I. INTRODUCTION

*Background:* There has been a notable shift in the past 60 years in the mental service delivery, where hospitals were handing over the responsibility of looking after mental patients to families and home based-care. This shift has resulted in families becoming the major care providers of relatives with long-term, chronic and disabling disorders, a role that has been provided by the mental institutions. In other words, hospitalizations and institutionalizations of mental patients, is now a family, and not an institutional responsibility.

Studies have shown that caring for major mental illness, especially schizophrenia, has a significant impact on the mental health and functioning of a caregiver. The studies demonstrate the importance of understanding the complexity of the experience of family caring for individuals with schizophrenia (Brady, 1996). Currently there is little research on family caregivers in Zimbabwe, particularly those who are caring for members who are living with schizophrenia. This research seeks to unearth a detailed understanding of a caregiver’s experience in the Zimbabwean context.

Schizophrenia is a chronic, severe and disabling mental disorder that has serious consequences for those with the illness, as well as those who take care of them. Many countries in the past 60 years, have de-institutionalized schizophrenic patients and other mentally related cases in favor of family based care (Baronet, 1999; Vella & Pai, 2013). This shift from institutionalizing schizophrenic patients to home based care, has also transferred the responsibility and burden to family caregivers, most of whom have no knowledge of dealing with such conditions (Awad & Voruganti, 2008). European countries are estimated to have between 50 - 90% chronically ill psychiatric patients now living with their families (Awad & Voruganti, 2008).

About 10% of the population of New Zealand are family caregivers of mental patients (Jorgensen, Parsons, Jacobs, & Arksey, 2010). There is no data as yet in Zimbabwe of the number of families living with people with schizophrenia. Caregivers of people with schizophrenia require a significant emotional and financial support for them to effectively provide the caring services. Caring for a relative with a severe, long term, and disabling disorder of schizophrenia places huge demands on family members and has considerable economic and emotional implications for caregivers (Baronet, 1999; Davies & Drummond, 1994).

This study will further explore the experiences of parents, relatives and friends who have taken upon themselves the responsibility of looking after their loved ones living with schizophrenia. The scope of this research will also investigate both the positive and negative experiences of caregiving, caregivers coping strategies, essential supportive factors, attitudes and perceptions of caregivers about their role of caring. It is the researcher’s hope that this investigation will provide a holistic conceptualization of the experiences of the community of caregivers of people with schizophrenia (PwS), as well as provide valuable information and awareness to mental health clinicians on the current issues of families looking after schizophrenic patients. Caregivers of major mental illnesses, especially those caring for patients with schizophrenia, are an under-researched group in Zimbabwe. Creating a platform to share their experiences will help to increase knowledge on schizophrenia and the role played by family caregivers, as well as help in the development of effective interventions and support strategies for individuals with schizophrenia and their family members.

Schizophrenia has different names in different cultural groupings, hence different causal perceptions and attitudes, leading to different intervention preferences. Most of the western countries use the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) or the International Statistical Classification of Diseases and Related Health Problems to diagnose and classify the illness. From the scientific medical model, a person who exhibits symptoms of hallucinations, either visual or auditory, delusions, disorganised speech and gross disorganised behaviour for more than a month, is diagnosable with schizophrenia (American Psychological Association, 2013). That strict definition criterion for the disorder by the DSM -IV clearly shows that although schizophrenia has been observed around the whole world, each culture has its own diagnostic tool, and the universality of the acceptance of the DSM -IV becomes questionable. Different cultures and races do show marked differences in symptoms and manifestations. This is due to cultural socio-centricity (Beur et al, 2011; Brekke &Barrio,1999).

In the context of most non-western countries, schizophrenia is strongly associated with supernatural and religious factors. Among the Ethiopia people for instance, schizophrenia is perceived as caused by witchcraft, bewitchment or possession by evil spirits (Furnham, Chan, 2004).

In the context of Zimbabwe many cultural beliefs are associated with the causes and treatment of schizophrenia. The society refers to the disease as 'kupenga', meaning madness, and a derogatory term though, which is not used in professional language. This 'kupenga' term, may refer to people who present with talking to self, hallucinations, delusions and hearing voices. Schizophrenia maybe characterized by hording litter- which the Shona people may refer to as 'kutanda botso', a term which loosely refers to a person who is being punished by the ancestral spirits for dishonouring, or disgracing one's parents. This 'kutanda botso' belief holds so strong among some communities, who feel the only way to make reparations is to allow the affected person to go through the full course of wrath until the ancestors are appeased by the punishment,( Muchinako; Mabvurira & Chinyenze, 2013).

The different cultural perceptions and attitudes as to the causation of schizophrenia precipitates different cultural interventions. These belief systems about causation dictate the type of interventions preferred. Studying such belief systems in any society helps in planning and implementation of appropriate health systems. The western view tend to associate schizophrenia more too biological and psychosocial factors, whereas, in non- western countries, the focus is mainly on supernatural and religious factors (BMC Psychiatry 2012).

Schizophrenia is often accompanied by relapses even while on treatment. Relapse is defined as the worsening of a psychological symptoms or re-hospitalization after discharge (Schennach, Obermeier, Meyer, Jager, Schmauss& Laux, et al,2012). Study seeks to find out why patients relapse under

the watchful eye of the caregiver, only to be brought back in a worse condition. The primary aim of this is to examine whether the bi-focal approach, which offers psychosocial support and psycho-education to family caregivers of schizophrenic patients, in addition to medical treatment, is more superior to the "patient-only" conventional approach.

## II. METHODS

This research project took the form of a qualitative inquiry. A qualitative approach was selected as the most suitable way to get an in depth detailed understanding of caregivers' experiences in the context of a Zimbabwean setting. The qualitative research approach was used to explore the caregivers' experience of caring for the ill relatives and the meanings they ascribed to their experience of the role of looking after the schizophrenic relatives. The study used a phenomenological research design. The participants were supplied with all relevant information concerning the research before they gave their consent to be participants.

The researcher explored the multiple realities as experienced by caregivers of schizophrenic patients. The phenomenological approach was used as it allowed full exploration and evaluation of participants' attitudes toward the phenomenon in question. A sample of caregivers, with vast experiences of caregiving was used in this study. The inclusion criteria characteristics making the participant qualify in the study was: caregiver respondents was 18 years and above and caregivers were the key caregiver. Caregivers lived with the patient(s) for more than 6 months.

In depth interviews were conducted and obtained the perceptions and attitudes of caregivers of schizophrenia on their role of caring, and the possible factors leading to relapses. The questionnaires were unstructured, giving the participants greater latitudes to delve into their subjective emotional vulnerabilities. Data was collected from participants until saturation was achieved. The researcher also used a focus group in one session. Data was collected using one-on-one interviews, focus group discussions and self-administered questionnaires and hospital records. Secondary data was obtained from documents, or reports and other records from relevant sources. Using an interpretative phenomenological analysis, the researcher was able to categorize the data in several groups.

## III. RESULTS

The main purpose of this study was to find out how family caregivers perceive schizophrenia and the attitudes that generally arise from those perceptions. Parirenyatwa Psychiatric Annexe unit was used as the main hospital from which the participants were drawn. In this chapter, the findings are presented as they appear in chapter one, based on objectives of the study.

All the research participants had many years of caring for people with schizophrenia. There were ten participants in total from ten families, comprising of seven female and three male

participants, their ages ranging from 38 to 65, and were all Zimbabweans coming to Annexe for medical attention. The family names of the study participants were falsified for the purposes of anonymity. One caregiver from each family was interviewed. The interviews were conducted and analyzed using the family systems theory of Dr. Murray Bowen. This system regards every member of the family as an important cog in a system. It recognizes that harm to one member is harm to the rest of the family system, (Bowen 1994). He says that family equilibrium cannot be maintained when one member of the family is emotionally unstable, (Bowen 1994)

All of the participants had been providing care for between 10 to 30 years. Four were married, four were divorced and two were single. The participants were asked to explain how they take care of their relatives with schizophrenia. They gave the account of their experiences, as well as their appraisal of schizophrenia. Their narrative of the illness expressed their perceptions and attitudes toward caregiving role to PwS. The participants gave their rich narratives from their wealthy experiences acquired from caregiving for schizophrenic patients. The participants' narratives were put into three categories, namely; the role of caregivers, the burden of caring and coping strategies for caregivers of schizophrenia. Pseudo names were used to uphold confidentiality.

#### *Roles Of Family Caregivers On Schizophrenic Patients*

Family caregivers gave testimonies of their roles in caring for schizophrenic patients. Jairoso, with his voice adjusted as if to reflect the worries and load that he had borne for over three decades, said;

*“Mukadzi wangu akapedzisira atoona kuti hapana chekugarira, akanditiza. Ndinorara ndakagara mazuva mazvinji kana zvakamukwiza. Ndakasadaro anobuda achienda kwatisingazivi, anogona kuputsa zvinhu mumba. Akatombo pwanya TV tichangoitenga, achiti inounza vanhu vanotaura nezvake. Saka ndaisakwanisa kunorara mubedroom nemudzimai wangu”*

#### Meaning:

*“I lost a wife as a result of caregiving, she found that it was a lifetime commitment, and she couldn't take it. When my ill brother is going through a restless and violent episode, I do not sleep the whole night. If I don't watch over him, he slips into the dark, and disappears, or he destroys properties. At one time he destroyed a brand new television which we had just bought. He said the presenters were talking about him (thought broadcasting). I rarely shared a bedroom with my wife for a period stretching for over five years, except for days my sick brother was detained at hospital”*

Jairoso said it was his responsibility to keep appointments with doctors or health centers. He has to come up with a daily schedule of his daily activities.

*“Ndinofanira kumufungira kuti amboswatura makumbo, ndinofanira kufunga nguva yekugeza kwake, aah, zvakaoma doctor”*.

*“I should plan his daily routine, including when he should take a walk, when he should bath, aah, it's a task doctor”. Despite telling him that “the researcher was a student, he kept saying ‘doctor’.*

Mejure, a mother of three, who had been caregiving for a son for twelve years, retrospectively, drew up painful experiences of her role. She tells the researcher that it was her duty to make sure that her son takes his medication on time every day and to watch for any sign of deterioration and relapses, and takes him to hospital.

*“Saka handikwanisi kuenda kune vamwe kuchurch kana kubasa, nokuti haagani kuzvifungira zvinhu zvizhinji. Ndinofanira kuona kuti pane zvisina kumira mushe muupenyu hwake - avekurwara, kana kuti pana zvakanganisika, ndotomhanya naye kwa doctor, iye muridzi haatozvizivi. Zvakangaomawo hazvo wena”*.

Theresa, who is a psychiatric doctor herself, but had stopped going to work because there was no one to look after her husband, had a very sad story to tell. In the interview room, she broke down emotionally, and wept freely like a little baby. As a professional person, she had a deep understanding of what it means to care for someone who is schizophrenic.

*“I lost my husband just a year after my colorful wedding. I will forever cherish my 12 months of marriage, and I know Tim is, and will forever be a shadow of his former self”, she said within sobs.*

Theresa met Tim at the University of Yale, and after completing their studies, they both chose to come and work in their home country. At the age of 28 years, she wedded her lover. It was just after Tim had completed his PhD, that he was diagnosed with schizophrenia. “I know what is at stake, you can imagine that I have to dress him up, brush his teeth and when he is in his bad spell, I have to help him use the toilet. As a wife, I am condemned to make critical decisions that he is by nature supposed to make as the head of the family. I keep hoping, ‘pamwe zvichaita hazvo hamheno’. She concluded, with tears standing at the door of her eyelids.

Tracey also described her struggles of caregiving. How she has literally ceased to exist for herself, but for her husband. She had this to say;

*“Ndakapedaza two weeks ndichatsvaga kuti zvino murume wangu anga aendepi. Ndakabvunda vose vanomuziva, vekumusha kwake, nevekwaaimbo shanda, nekumabhawa, zvose neku mapurisa, asi zvakashaya basa, hapana aiziva kwaakange aenda. Zuva racho ndakararisa, akanyahwaira aka buda usiku, ndokuenda achitevedza nzira inoenda ku Zaka, kwasekuru wake. Anoti akanzi ne nzwi rasekuru vake vanosangana kumusha kuti vamuratidze mushonga unorapa vose vanorwara ne pfungwa ku chipatara.*

*Ndakazomuona ari muChivhu, abatwa nemapurisa. Vakatora phone yaaiva nayo vakaicharger, ndokuzondi phonera”.*

“It took me two weeks to locate where my husband was. I searched and looked for him everywhere, at his relatives, his former work place, beer halls, and at everyone’s place who knew him, including the police stations, but to no avail. He had slipped out of the bedroom into the night when I momentarily napped off. He went along Masvingo road, toward his Zaka rural home, alleging that he was obeying the voices of his long departed uncle who wanted to show him a special herb to treat all mental patients at Parirenyatwa hospital. I found him in Chivhu, where he was detained by the police. The police were alerted by a bus conductor who saw him on each trip along the same road for three days. They took the phone that was in his possession, they charged it and got my number whereupon they called me immediately”.

All the participants had common confluences in their caregiving roles. They would express one phenomenon in different ways, but showing fundamental congruence. Mathias, a divorced man, who had cared for his only brother for 27 years calmly said;

*“I try to keep his environment free of any dangerous objects for his safety and that of others. You leave an axe close by, he takes it and cuts down all fruit trees in the orchard and tells you after that he was clearing the forest so that thieves have nowhere to hide. And who knows what else he can do with such dangerous objects against himself or other unsuspecting people, so yes, I try to make the place as clear as possible”.*

Nyepai, who has been caregiving a daughter for 13 years, who was diagnosed of a subtype of schizophrenia called disorganized schizophrenia (hebephrenia), had a horrendous experience. This subtype of schizophrenia is thought to cause an extreme expression of disruption of human life. This type is a total distortion of reality and arrests basic life instincts such as sense of taste or smell she has this to say;

*“I dress up my daughter, she sometimes wears two different sets of shoes and at times of the same side. She wears several layers of clothes even during a hot day. She has on many occasions even solicited for sex in the glare of the public eye, so you see, I have to help her behave*

*decently. She can tell you that she wants to go look for men to sleep with. Such awkward and bizarre behavior is absolutely normal with her.”*

Nyetu lost a husband who, upon leaving, told her that she was now married to a new husband called schizophrenia. Her story is embedded with emotions and self-pit. Her mother was diagnosed with Catatonic schizophrenia. This type of schizophrenia exhibits a frightening degree of physical immobility where patient does not speak or make any movement for several hours. The catatonic patient may resist any attempt to move her /him and remain unresponsive even when you persuade them to say something. She looked into the ceiling and narrated her story with calculated and suppressed emotions;

*“Zvakaoma mufunge , kana amai vazviomesa mutezo ndinotvakura semwana. Vanogona kusataura kwe two hours vakangoita sechidhori, vasingabwairi maziso, kana kufamba, zvadaro ndovaita sekacheche, kuvadyisa chikafu, kugezesa. Pamwe vanotevedzera zvose zvandinotaura kana zvandinenge ndichiita”.*

“At times she becomes physically immobile, holds her body in a fixed position. When she is in that state (catatonic stupor), I have to carry her like a baby. She maybe mute for over two hours, without even blinking her eyes. I then have to feed and bathe her. At times she screams or repeats everything I say (echolalia) or any movement I do (echopraxia)”.

Ranganai agrees with his colleagues who all paint a picture that caregiving for a schizophrenic relative takes the entire life of a caregiver;

*“I had to drop from my university studies when my father began to exhibit strange behaviors. He needs constant monitoring because he was diagnosed with paranoid schizophrenia. He has false beliefs that everyone is plotting against him. He sees everyone as seeking to do him harm, and as such, has put himself in a perpetual mode of self defense. So, if he moves about alone, and meets people, he attacks them in a perceived self defense style. My worst nightmare is when I take him for medical checks, because everyone is out to harm him. I sometimes have to tie his hands. Even the medical practitioners who attend to him, he perceives them as seeking to inject him with HIV/AIDS, so he does not trust them.”*

Table 1: Demography of Participants (caregiver)

Pseudonym	Age	Sex	Ethnicity	Marital status	Education	Time as caregiver in years	Relapse episodes	Relationship with each other
Jairosi	65	Male	Zimbabwean	Divorced	Standard 2	30	Countless	Brother
Majure	47	Female	Zimbabwean	Married	Form 4	12	Many	Son
Theresa	40	Female	Zimbabwean	Married	University	11	many	Husband
Tracey	45	Female	Zimbabwean	Married	Form 4	20	Many	Husband
Mathias	60	Male	Zimbabwean	Divorced	Form 4	27	Countless	Brother
Nyepai	38	Female	Zimbabwean	Single	Degree	13	Many	Daughter

Nyetu	42	Female	Zimbabwean	Single	Form 2	19	Countless	Mother
Ranganai	39	Male	Zimbabwean	Married	Form 6	10	Many	Father
Sarudzai	48	Female	Zimbabwean	Divorced	Form 1	11	Many	Daughter
Juliana	46	Female	Swedish	Divorced	Psychiatrist specialist	15	countless	Father

(To protect the participants' identity, all the names given on the table above are pseudonyms, but the other demographic information on the table above is true).

### *The Burden Of Caregiving*

Caregiver burden, according to Williamson & Shaffer (2001), is the stress which is perceived by caregivers due to the home care situation. It refers to the caregiver's emotional response to changes and demands that occur as they give help and support to the ill relative.

Two of the participants, Jairosi and Mathias, concur on the issue of financial burden of caregiving. *"We are always coming and going to hospital. Most of the times when we come here, there is no medication, the doctors just write us prescriptions, and ask us to go and buy. Where the hell do they think we get them from? I have been looking after my brother for three decades, no job, yet they expect me to buy such expensive medicine."* Said Mathias.

Jairosi had no kind words either for the powers that be;

*"Hautomboziva kuti ihurumende yerudzii, isina tsitsi. Havana tsitsiwo nemunhu akadai here, vanoti anoiwanepi mari yekutenga mushonga? Ini handichina chinhu, mombe, mbudzi ne huku dzangu dzose ndakatengesa kuti ndichengete hama yangu, ndangove munhu chete"*.

*"One wonders what kind a government we have, very insensitive, where do they expect such an ill person to get money for his medication? As for me, I have nothing left, I sold all my cattle, goats even chicken over the years to help my brother"*

Sarudzai claimed that her husband left her because she was unable to meet his emotional and sexual needs, and has since married another wife, and rarely visits her.

*"I spend all my time either indoors with my daughter, or at hospital. All my friends have since stopped communicating with me. My world has no any entertainment; I will live for my daughter until God knows when"*.

There was consensus among some of the caregivers that they have since cut off ties with some of their former acquaintances because of stigmatization.

*"A great number of people in our society do not understand schizophrenia. They still associate it with first century mysticism. They label you, call you all sorts of names, and you know what, the best way was to sever all ties with them, and for six years now, my social world has my sick father, mental health practitioners and a few fellow caregivers that I meet at hospital - those who also have suffered the same rejection from their colleagues like me. Wish this government assisted with grants for mental*

*patients, because we have few people who are still willing to assist us financially, knowing the chronic nature of the illness"*

### *Coping Strategies For Caregivers Of Schizophrenia*

Coping strategies are ways and methods that can be employed to deal effectively with an unfolding stubborn situation. Caregivers are often faced with daily monotonous situations of a debilitating nature. The researcher arranged for a focused group discussion session with all the participants. The engaged in a lively discussion about their perception of the role of caregiving. The 45-year-old Majure, who had been taking care of her son for 12 years opened the floor by saying, *"When my son started hearing voices, apparently he would engage in conversations with invisible personalities, I was shaken, I didn't know what do."*

Nyetu joined and said; *"When I took my mother to hospital the first, the medical professionals only spoke to my ill mother and never explained anything to me except to tell me to give her medication at the set time. I decided to pass through a spiritual healer on our way home. At least I needed to know what was happening to her"*.

Jairosi concurred and added; *"I was so convinced my brother was bewitched and possessed by demons. I couldn't guess what that could be. I had no one to tell me what this 'skitso' was all about."*

It was apparent from the caregivers' narratives that they lacked information about the illnesses of their loved ones.

*"Ini ndakanopiwa matombo nemapostori nemvura yemuteuro. Ndakapererwa uye ndakange ndave kutya mwana wangu nekuda kwezvaaitaura. Zvaityisa"*.

Sarudzai said she went to get some readily available advice from the religious sects who gave her an assortment of artifacts to stop the spell. She feels the greatest impediment to her daughter's late stabilization was due to lack of information.

Sarudzai weighed in sarcastically;

*"I was so scared with my daughter's condition that I was even prepared to get advice even from the shrine of the devil as long as there was promise for restoration. But, you see, that information was not available, so we ended up in the hands of the so called prophets, sangomas, faith healers. We swallowed all sorts of concoctions for want of help. The hospital staff was mean with useful information, so I had no choice."*

Nyepai, who has been a caregiver for 20 years;

*“The mental health professionals are not attentive to our concerns; they don’t even listen to our views. They forget that we spent more time with the patient, they should listen to us. I hope they will realize that we are the custodians of*

*the patients, and that they should sit down with us and give us the necessary information to avoid relapses of the patients.”*

Mathias concurred; *“They look down upon us, they have nothing to learn from us”.*

The table below summarizes the burden of caregiving into four clusters; the physical, the psychological, the social and the financial.

Physical burdens	Psychological burdens	Social	Financial
Somatic complaints	Emotional disturbances	Reduced social contact	Divorce
heartaches	Depression	Isolation	Poor diet
headaches	Anxiety	Disruption of leisure activities	Unpaid bills
Lack of appetite	Grief	Loneliness	Medical expenses
Laziness	Stress	Stigmatization	Suicide
Fatigue	Distress	Prejudice	
	Hopelessness	Discrimination	

#### IV. DISCUSSION

The study explored at depth the lived experiences of family caregivers of people with schizophrenia. All the participants were long-term caregivers of schizophrenia. In total they have been playing the caregiver role for a sum total of 168 years. It is from that wealth of experience accumulated over so many years that the researcher believes the caregivers’ record was valid and plausible.

Using an interpretative phenomenological analysis, the researcher was able to investigate both the positive and negative experiences of caregiving, as well as coping strategies, supportive factors, attitudes and perceptions of caregivers. Four themes could be derived from the participants’ stories which were categorized into four subtopics namely; financial, social, psychological and physical factors.

##### *Psychological Factors*

It was clear from the stories of the participants’ lived experience that family caregivers go through frequent emotional episodes in their role as careers. Some of the most salient descriptions that they experienced as caregivers express significant signs of worry, distress, fear, hopelessness, helplessness and deep frustration. It is without doubt that family caregivers experience significant negative feelings (Boydell, et al. 2013; Parabiagh, et al., 2007). As a result of the expressed feelings by caregivers, it is apparent that they experience ‘emotional burden’.

From Majure’s story, it is clear that she was emotionally burdened – *“I was shaken, and I didn’t know what to do”.*

Caregivers experience, anxiety, depression, stressful life events, hopelessness and distress.

*“---I lost my husband just a year after my colorful wedding---”.*

Theresa perceives the illness as having ‘taken’ her husband away. She sees her schizophrenic husband as a shadow of his former self. And she has no hope of ‘recovering’ back the person, for she says, *“---I know Tim is, and shall always be a shadow ---, hapachina, zvakatopera hazvo, Mwari ndiye anoziva, chokuita hapana”.* Meaning; There is no recourse to the condition, fate allowed it to be so.

The way the participants described their emotional burdens is consistent with a research that was done on caregivers by Awad & Voruganti (2008). The participants express high levels of distress and trauma on first episode manifestations of the psychosis of their relatives. This is also consistent and agrees with the findings of a research by Addington, et al., (2003). The participants described feelings of loss and grief as they struggled to come to terms with the diagnosis of their relatives, they did not report any experiences of substance abuse. Other researches have shown that caregivers end up using intoxicating substances to find temporary respite (Awad & Voruganti, 2008; Boydell, et al., 2013). It can be hypothesized that either the participants were not willing to disclose such information in an open group discussion or they did not think it was necessary to talk about it, but other researches show high prevalence of use of substances.

The significant level of distress and emotional burden is consistent with another research that was carried out in New Zealand, suggesting the commonness of the same phenomenon (Jorgensen, et al., 2010). The way the participants expressed their feelings and emotional burden strongly corresponds with the severity of symptoms in individuals with schizophrenia. There are many other studies that have documented the correlation between symptom and burden, and this study exhibits those similarities (Addington, et al., 2003; Martens & Addington, 2001). Mathias and Jairoso used a cognitive coping strategy of positive thinking, believing even against hope, that despite taking care of their

loved ones for almost three decades, they kept believing that their beloved ones shall be well.

#### *Social Factors*

The participants, sadly testified to the fact that most of them have ceased to be actively involved in outdoor social activities due a number of factors including the feeling that society stigmatizes them, and a perception that they are discriminated against. This unfortunately attitude tends to have a negative psychological health effect upon their lives. Studies have shown that social activities lead to a more positive outlook and a reduction in stress for caregivers (Harvey, et al., 2001; Onwumere, et al., 2008).

The participants reported an increasing emotional burden over the continued deterioration of symptoms in their care recipients. Consequently, the caregivers also experienced more negative appraisals of the impact of the illness, more difficult in dealing with the illness and reported increased family conflicts, resulting in divorces and extra marital affairs. This is consistent with studies done on caregivers who suffer social strangulation (Rose et al., 2006; Addington et al., 2003). The caregivers reported to have been so actively involved in the life of the ill patient to the extent of reducing their social contacts. The reduced social contact naturally results in social isolation, leading to loneliness. A number of studies already done have noted the positive impact on both the physical and psychological wellbeing of a caregiver who remains socially active, (Fang-pei & Greenberg, 2004). Caregivers who are socially disconnected suffer more from loneliness and negative caregiving experiences, (Boydell, et al., 2013). According to Boydell, (2013), caregivers of chronic mental illness can become socially isolated due to stigma and poor cultural understanding of schizophrenia, (Berglund, et al., 2003; Boydell et al., 2013)

Though the participants did not report feelings of discrimination, it was clear from the discourse that they have poor self-esteem. This is well pronounced when Nyepai accuses the mental health workers of not recognizing them and giving them due respect as major player in the wellbeing of the patients. Such feelings of being left out are consistent with other studies that have shown that isolation results when caregivers distance themselves due to fear of embarrassment (Huang, 2008; Magliano, et al., 2006). Bowen's theoretical framework on family homeostasis, (Bowen, 2004), caregivers compensatory approach in an effort to make up for the loss of a members, results in disruption of other social activities.

It was not clear from the participants whether they had sought information from health practitioners about schizophrenia, but it appears the only knowledge they had about schizophrenia was from their cultural perspective, hence the talk about faith healers, sangomas, prophets, bewitchment, and so on. As a result of lack of information, the family conflicts erupted, resulting in several divorces and strained relationships. Caregivers of people with schizophrenia, have been reported on studies done across the world to experience considerable

conflicts, tensions and fracturing of relationships ( Boydell, et al., 2013; Fang-pei & Greenberg, 2004). Participants in study noted also that the siblings and other members of the family with a schizophrenic experienced a considerable degree of distress and difficulty, particularly when living in the same home. It was apparent that siblings shared in the feelings of emotional burden even though there were not providing care themselves. This finding is in tandem with the theoretical framework of Bowen, (2004), on homeostasis. This is also consistent with other findings on caregivers of schizophrenia on the whole family, with burden and distress extending well beyond the primary caregiver (Award & Voruganti, 2008).

#### *Financial Factors*

The lack of resources and financial support for caregivers was reported by all participants throughout their accounts. The participants get free counseling services at Annexe for their sick relatives by clinical psychologists, mental health services at Parirenyatwa hospital is free of charge, though they are asked to buy the supply of drugs if they are not available (usually very expensive and beyond their reach), but apart from that, almost no other form of resources were provided directly to caregivers by mental health services to assist the caregiving role. There was no other form of support made available to the caregivers. Sadly for the careers, they are expected to take on the responsibility of providing shelter, financial support and a high level of day-to-day care and supervision for their ill relatives.

Additionally, the participants were not provided with useful information or some kind of support to help manage the deteriorating symptoms and serious issues such as aggression behaviors, violence and intention for self-harm by unwell patients. The caregivers were torn between the concern for their loved one, the desire to provide the best possible care and with fears for their own safety. According to another research on mothers caring for adult mental children, they called this dilemma 'choosing the best of hells' (Copeland & Heilemann, 2011). Either caregiver of schizophrenic relatives must take on the responsibilities of caring and risk their safety and wellbeing, or they choose not to provide accommodation and support of their ill relatives. The participants wished there was some form of financial help extended to the caregivers. They described how they had either lost their jobs or stopped going to work due to the day-to-day demands of caregiving. The loss of a reliable source of income had impacted negatively on their livelihood. They were coping with ongoing such as transport, food, medical care and clothing.

Unlike in New Zealand, where there is a Bill Rights ( 1990) which stipulates that full time caring for an adult person with a chronic disease is beyond the duty of 'natural support', therefore such people are state assisted - a court verdict ( Ministry of Health v Atkinson, 2010); Zimbabwe has no such policy and caregivers go it alone, and the effect of having no policy on chronic disease especially in the area of assistance results in caregiving developing feelings of stress in their role of caring.

### *Physical Factors*

There is evidence that careers of chronic diseases experience an increase in health problems. Some studies have shown that between 15% to 33% of caregivers experience detrimental effects on their physical health including backaches from lifting and carrying the ill person, from turning them around on the bed, physical exhaustion and stress related ailments such as ulcers hypertension (Horowitz & Dubrof, 1992; Schulz, et al., 1995; Biegel et al, 1991; Craswick, 1997).

From the account of the participants of this research, it was noted that there was high tension in families over caregiving. This resulted in divorces, separation and strained relationships. The role of caregiving seems to have been taken for granted without looking at the possible conflicts that could result out of it. These conflict are also in agreement with other studies already about caregiver where conflicts occurred as a result of sharing caring responsibilities (Strawbridge & Wallhagen, 1991; Guberman & Maheu 1997). It was noted that divorces were a result of either one spouse becoming too emotionally involved in the life of the ill person at the expense of other members of the family, or resulting in neglecting other responsibilities in the family. This over involvement disrupted normal patterns of relating to the rest of the family members, thereby resulting to high levels of unmet needs (Philp et al., 1995). The record given by the participants of this study about divorce is also consistent with a study done by (Clipp & George, 1993; Hooker et al., 1998). In their research, it was reported that high levels of stress have a huge negative effect on intimate or sexual relations. The lack of intimacy, the study noted, results in stretching family relations or divorces ( Murray & Mann, 1999).

The participants in this study cited limitations in social life activities, loneliness, self neglect, isolation, chronic fatigue, and more pronounced was the interrupted sleep especially during times when patients will be hyper active. Participants also highlighted how they forfeited career opportunities, and also how out-of-pocket expenditures on the ill person. It agrees as well with a study done by (Brody & Brody, 1989; Pfeiffer, 1987).

Fatigue from general exhaustion results in poor concentration on the part of the caregiver, thereby resulting in the caregiver failing to fulfill certain obligations at work or other family needs, leading to a disruption of the family homeostasis (Bowen, 2004).

### V. LIMITATIONS

There are several limitations that could be identified in this particular study. The sample size used to conduct the study is too small to give a global reflection of all caregivers of schizophrenia elsewhere. This research was done at Parirenyatwa Psychiatric hospital in Harare, using a few people as representing caregivers of schizophrenia. The small sample used cannot therefore be representative all caregiver of those outside Harare, neither can it represent caregivers from

different populations, different ethnicities or those outside Zimbabwe. The other possible limitation could be that the participants used were those who had experienced the worst case scenarios in their caregiving role. Because of this, they may be biased toward capturing the negative experiences only rather than the positive. This particular interview was conducted in a face-to-face set up. Naturally, participants may withhold certain information that they feel uncomfortable to share in a non-anonymous setting.

### VI. CONCLUSION

In spite of the similarities in the experience of caregiving and the major stumbling blocks that confront caregivers: isolation, helplessness, lack of recognition, insufficient resources, juggling care with other responsibilities, lack of finances and sadly the lack of power to influence policy changes, the larger diverse community of caregivers must be included in the intervention process. In order to efficiently respond to the uniqueness of the caregivers' circumstances, resources must be availed to the department of mental health by the ministry responsible, and to the extent possible, the caregivers must be involved in the intervention matrix. This research demonstrated that participants were faced with the difficult of providing high level of care and support for the family members with severe and disabling mental illness like schizophrenia; a role which they initially undertook with little or no information, with no resources and without support. The caregivers need knowledge and information, they need skill and understanding so that they should have a sense of control even in an often unpredictable situation with a schizophrenic patient. This study can suggest a number of recommendations to the clinicians who work with individuals with schizophrenia and their families. This could include psycho-education for family members to increase understanding of the illness as well as suggest strategies that may be useful in dealing with volatile or aggressive behaviors. To create and make available psycho-social interventions and to make it easy to rehabilitate individuals with schizophrenia. Important information such as legal requirements for the mentally sick, support services and available resources or help must routinely be given to the family careers. The caregivers must be offered free counseling services each time they bring their sick to the mental health institutions. Since mental health approach is multi-disciplinary in nature, this study recommends that policy makers must make it mandatory that no mental health institution must operate without counseling psychologists. The psychologist must be available to provide the much needed psychotherapy to both patients and caregivers.

Policy makers must advocate government to consider financial assistance to caregivers of their families. The government must take responsibility for mental disabilities especially chronic ones like schizophrenia because caring for an adult for life has serious negative financial ramifications on the caregivers.



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