

Full Length Research Paper

The lived experience of families with a mentally ill family member

^{*1}Moses Wankiiri, ²Karen B. Drake and ³Kimberley R. Meyer

^{*1}Senior Lecturer: Adult and Mental Health Nursing, Advanced Nursing Studies Program Aga Khan University

²Professor of Nursing, Director of Skills Lab and Technology, Bethel University

³Department of Nursing, Bethel University

Abstract

The study of the lived experience of families with a mentally ill family member involved seven family members who had come to visit their mentally ill relatives in the mental Hospital. The major objective was to explore the lived experience of families with a persistent¹ mentally ill family member. The study adopted a qualitative descriptive-phenomenological design, participants were purposively sampled and data was collected using a tape recorder. Colaizzi's phenomenological approach for data management was then employed. The study revealed that family members held misconceptions about mental illness and described care as a contractual obligation. They lived in misery as the patients' behavior was intolerable, sadistic, exasperated, and embarrassing. Although medication proved helpful, they had to plead with the patient to take it. Their homes were discriminated² which made them desperate and disappointed. Patients had bizarre complaints, could vanish, which forced family members to be vigilant all the time and made them feel guilty if anything happened to the patient. Family revenue was devastated and admission of the patients was considered a liberty to the family members and a break from the monotonous, tiresome and costly collection of medication from the hospital. Family members were pessimistic, and always in dilemma. Living with a mentally ill family member was considered a prime issue in the affected families. The study recommended health education to the community, institute programs to screen patients, counseling, and community patients' follow up. There was need to initiate home based income generation through micro financing.

Keywords: Persistent mental illness, Discriminated home, Lived experience, Family member and Mentally ill.

INTRODUCTION

Across cultures around the world mental illness has been surrounded with a great deal of prejudice, myths and taboos, making its management challenging to the health care team and families looking after the patients at home. Families frequently serve on the front line of care, providing housing, financial and emotional support and, securing needed treatment for their family members with mental illness (Pickett-Schenk, 2003).

Stressful psychosocial factors, linked with economic hardships, and the accelerated spread of HIV infection, have all combined to yield disquieting incidences of mental illness. Other stress related problems like substance abuse, the general deterioration of the individual, family and community structures due to

political turmoil, wars or armed conflict have made the situation worse. This has increased the outpatient clinic visits and inpatient admission in the hospital where family members are seen visiting patients and bringing others for follow-up treatment in the mental health clinic. The persistent¹ mentally ill patients are typically admitted to the hospital for the intensive treatment and discharged to their homes where they get their follow up treatment. At home the mentally ill patients are cared for by family members to meet their physical, psychological, social, and spiritual needs while dealing with their disordered thoughts, feelings, and behavior.

Problem Statement

The care of the mentally ill by the family members is done with little or no supervision by the skilled health workers.

*Corresponding Author Email: moses.wankiiri@aku.edu

It is against this background that this study was done to explore the lived experience of families who live with and care for the mentally ill family member. Aspects of family care giving range from quality of care issues for the family member with the illness to how the illness of one member impacts the family as a whole.

Patients are seen wandering on the streets even when family members seem to be caring and mental health services are free. Mental illness is also known to be one of the most stigmatizing diseases but the effect of the stigma to the family members is not known. It has also been observed that mentally ill patients from wealthy and well to do families also sleep outside on the veranda and eat food from the dust bins even when the family members are able and willing to provide all the needs for the patient. The core of the problem, therefore, is that very little is known about the lived experience of families with the mentally ill family member and yet they play an important role in care.

METHODOLOGY

The study employed a qualitative descriptive-phenomenological design. The descriptive design enabled the researcher to obtain data to describe the phenomenon of interest, which was the lived experience of families with a mentally ill family member. It was carried out in the National Mental Referral Hospital Out Patient Department and Hospital Wards.

Family members who accompanied their mentally ill family members to the Mental Health Clinic and those who came to visit their mentally ill family member admitted in the hospital wards were interviewed. The sample size was seven respondents, this when the saturation point was achieved. Purposive sampling was used in order to get family members who were living with, and caring for, the persistent mentally ill family member who was at least 21 years old. The caring family member should have lived with and cared for the mentally ill individual continuously for at least three years. The family members sampled were those who cared for persistent mental illness like Post Traumatic Stress Disorders, and major depression, but others like schizophrenia, bipolar disorders, and dementia were considered.

Data collection was done using an audio tape recorder after the participant had signed a consent form. It was then transcribed for analysis by making categories, sub themes and finally themes where the meanings were extracted. The tapes were then destroyed after the wanted data had been extracted. Colaizzi's phenomenological approach to data generation was used (Polit and Beck 2008).

During the interview, questions were adequately explained to the respondents so as to avoid receiving vague or irrelevant answers. Respondents also had opportunity to clarify or adjust their responses for

accuracy. To ensure confidentiality tapes were secured under lock and key until desired data had been extracted. This ensured that the information was secure and confidential. No one was able to have access to information after the researcher has analyzed the required data.

RESULTS

Seven participants were interviewed during the study, three had come to visit their admitted relatives and four escorted their mentally ill family member to the mental health clinic for review and to collect more medication. All the respondents were female and at one point during the interview they all wept.

Consequences to families

The study revealed that there were consequences as a result of living with a mentally ill family member. Consequences highlighted were that caring for the mentally ill was a contractual obligation that left certain members in the family as their sole responsibility, duty, job, task, function, or liability. One mother said:

"I am the one as the mother who cares for him...he does not like other people so it's only me with this load." She also wondered who would take care of her son if she died and said: *"If I died now who would care for him? I know am the mother and the only friend."*

Another woman who was looking after her brother said:

"It is me and only me who looks after my brother... there are other family members in the home but they never want to stay around with him...all my brothers and sister chased him from their homes and I am the only one taking care of him."

Among other consequences family members described the loss of freedom to socialize and participate in activities outside the home. This was understood as *'have to be there'*. They had to give up, forfeit or forego church prayers, weddings and other social functions. One mother said:

"I find myself spending all the time with him...if I am not there...chaos...even if am invited for a wedding or party I can never go to attend."

Another patient's mother said: *"The biggest problem I have is that I am never able to go and work because I have to look after him...it requires me to be around all the time...any time he can do something 'dangerous'."*

One sister to the patient said: *"Care takes money, drains the mind and wastes a lot of time."*

Another consequence that families described was that family revenue was devastated. Family income, proceeds, earnings, and profits were used to pay for the expenses associated with caring for the mentally ill family member. One mother said:

"My working time to make money has really been encroached on...yet the little money I get is again spent on him... everything I do now is about the patient because most of the time is for looking after the patient and the savings still are used on the patient."

One care taker said: *"To me the transport fare to collect free medication is almost equivalent to buying the drug...this has caused me a lot of financial problems because I come from very far to come to hospital and I have to do this every month."*

Another mother said: *"We would be rich because we had planned resources for our family very well but most of the resources were used on the patient."*

One sister regretted unnecessary expense the family incurred when patient destroyed peoples' property and stated:

"The patient destroyed peoples' property like he hit a wind screen of a moving vehicle which we had to pay...we had to borrow money in order to raise enough for the wind screen...this imposed heavy expense on the family that we were not expecting...of course we had to spend on treating his wounds after he was beaten by a mob." Another mother whose mentally ill son stole merchandise from a kiosk said: *"I painfully had to pay because it's my son who got the merchandise."*

The families also revealed another consequence that, it was unpleasant living with a mentally ill family member. Family members used words like, 'terrible, disgusting, horrible, obnoxious and horrid' as they expressed feeling resulting from living with a mentally ill family member. A mother who had lost five children and had two children mentally ill reported:

"I really feel very; very unfortunate to have two children that are mentally sick at home... I really feel bad about it and yet I lost five to mental illness...when I realized that my first son has run mad at that moment my heart started crying ...It has been a life time job for me...It has been difficult to enjoy my life as a mother...I wouldn't wish them to die because they are my children but those who died survived this endless illness, and sorrow without hope for complete recovery...I have not had peace...sometimes I regret why I produced children...the biggest and majority of the problems in my life has been caring for the mentally sick children...I some time feel so depressed with sorrow in my heart because I would now be getting support from all my children but it was not possible...(then cried)...I wonders why I produced them.... I think I would have been better off without them other than producing them to suffer and make others suffer... I sometimes ask myself why I got married because I have got nothing".

Another mother who expressed disgust informed that:

"My son is now a waste...useless, he can't do anything constructive and I really feel bad about it.... when I look at his age mates I feel tears rolling down my heart." A sister to the same patient said *"His disease makes all of us at home feel bad and worried as if we lost a family*

member."

Families described the job of collecting medication for the mentally ill family member as monotonous and tedious. It was a tiresome, boring or irksome routine to collect free medication from the hospital. One mother said: *"We usually get problems traveling here every month some time every two weeks to get that free medication...drugs are free in the hospital but going there monthly is tiresome."* Another mother said: *"We have to come here monthly which is very inconveniencing although it appears not to be very far, we have to board two taxis...Sometimes we wish to buy and avoid travelling but that medicine is not common and not sold in any drug shops."* An aunt who wanted to reduce the monotony and transport fares said: *"I am forced to collect drugs from two stations in order to save on transport and inconvenience."* And a mother said: *"This has caused me a lot of financial problems because I travelled from very far to come to hospital."*

The other consequence to families was that mental illness became the prime focus and problem. Family members described living with a mentally ill family member as the biggest or largest problem the family had. One mother said:

"The biggest and majority of the problems in my life has been caring for the mentally sick children...this is because his sickness paralyzes all the system like money generating activities, relationship with others and attending social functions." Another mother said: *"we haven't got any fortune out of this patient's illness because all has been problems throughout...all has been a burden for us as a family."* One sister to the patient said: *"There is no problem that is bigger than caring for the mentally sick brother because it is forever...I don't know when it will ever end completely."* An aunt to a patient said: *"Mental illness in a home is a disease for all because in one way it will affect all family members...when one person is sick everybody suffers...his disease is a concern of everybody at home including young children who report to us what he is doing every time."*

Family members have to be vigilant as a consequence of living with a mentally ill family member. When the patient was at home the family members had to be watchful, attentive, prepared, observant, and on the alert. One mother said:

"He changes abruptly so whether well or not well we have to be alert because we know anything can happen...living with a mad person is really hard... it's hard to predict what he is likely to do next, the attacks are not having any warning usually...you just see him being aggressive or destructive... you have to watch him all the time...even when I am with him at home I have to be on constant watch out since he can still do dangerous things behind your back."

A sister to the patient said: *"when he is discharged I am on full time alert...we have to watch for any changes in*

behavior and to make sure he takes the medicine in time...he has always talked of committing suicide by swallowing many tablets and we have to watch him every time to prevent this...all the time she wanted to hatch a plan to committee suicide so we had to watch him all the time."

Another mother described herself as working like a soldier and said: "All the time you are like a soldier, getting concerned even on simple details of his behavior... you must ask where he is even when you never wanted him for anything...every time there is fear that he might move away and cause havoc."

Another sister to the patient whose money had been stolen by the patient stated that: "I have to be strict with places where I keep the money otherwise I will lose it all the patient will pick it and disappear with it." One mother said: "We cannot prepare anything in order to be ready for the next attack because it does not come the same way so just have to be alert...we don't have particular arranges to care for the patient but it's every body's responsibility in the family to observe the patient...It's very difficult to plan for him because his behavior changes every time...he does things unexpectedly so you need to watch him closely"

Emotional responses towards living with the mentally ill

The study revealed emotions generated among the families while living with the mentally ill family member. Among the emotions generated was that family members felt as though they were in dilemma and described themselves as being in quandary, predicament, problem, or trouble while living with the mentally ill family member. One mother who did not know what to do about the situation stated that:

"I have tried all I could but in vain...he is difficult to control...even if it's at night he can go out leaving the door open." Another mother said: "we have tried a lot of treatment from the traditional healers... we gave him medicine to drink, smear on his head, some of inoculated in the cut skin but never helped...every healer promised to cure him but never managed."

Another mother who had cared for seven children with mental illness said:

"We devoted ourselves to make the children free of mental illness but in vain...am telling you we did everything that there is but no good outcome was seen... my entire house was filled with herbs and traditional medicine in every corner... in fact I even feared to sweep because all I was to sweep from my house were herbs...I have also had encounter of many different religions some would come and pray and cry but none of these gave positive results...now we handle these problems the way they come because we can never change anything however much we try...we started on traditional medicat-

ion but never worked we tried here and there but in vain".

One sister to a patient who suffered after using traditional medicine before going to hospital said: "We really suffered with him for complete two years while treating him with traditional medication that never helped." A mother caring for another patient who refused to eat food from home said:

"We had to take food to roadside where he asks food from such that he could eat food cooked at home. ...he ate that food twice then realized we take it there and he stopped." Another elderly mother said: "I am growing older but am worried about who will help me in my old age since my son instead needs help from me up to now...it is difficult to just leave him anywhere yet helping him is also difficult."

Another emotion family members expressed was misery when living with the mentally ill family member.

Family members observe their mentally ill relatives going through suffering, affliction, torment, torture, agony, distress, or anguish. One mother who had several children with mental illness narrated her experience while taking care of her children and said:

"One of my sons was one time beaten almost to death at night when they mistook him for a thief but later realized he was my son and at another instance he was beaten by villagers for no clear reasons... when my daughter was started on treatment she deteriorated and died... my forth children just woke up one morning and complained of headache and backache... at the time...he was already confused and later run completely mad...the fifth one, who had business trading in merchandise from the Mombasa coast...came back from Mombasa and he told the wife that he was feeling a lot of headache shortly he became confused and run mad"

One sister to a mentally ill brother who used to escape from home said: "He is one times beaten because of having no taxi fare...they realize later that he was mad and then release him after he had been beaten and sustained injuries."

Another mother said: "My son was beaten after suspecting him to be a thief... it was police which saved him otherwise he would be lynched by the mob...he sustained deep cuts on the head and body...when we saw him everybody cried, we thought he would not survive."

Further emotional responses to living with a mentally ill family member were feelings of embarrassment. The family members described living with the mentally ill family member as upsetting, awkward, uncomfortable, uneasy or thwarting. One mother who could not travel for a visit with the mentally ill son said:, "I can never go with him because he would behave in an embarrassing way...he claims from strangers that he had lent them money and that he is demanding it from them... he orders them to pay him the money for repairing their radios; a job that he has never done for anybody in life."

One sister said: "we usually get ashamed because

they know he is from our family...when he breaks down he is very abusive and obscene...although we hideaway still they will come and report to us that he abused people...he collects rubbish and carries it home... it's a shaming."

The sister added that:

"The patient has not done anything bad in the village but the fact that he behave in a funny way like moving naked carrying dirty things sometimes or wear dirty clothes make us lose dignity...he usually goes to the road and never gives way to the vehicles, he stands and may not mind whether vehicle are coming to knock him or not...whenever he does such, people would always come to attack us as if we intended to send him to go and obstruct traffic...it makes us feel bad and ashamed but we don't have control over it...he carries rubbish, disorganizes the house and cannot take care of his hygiene...he is odd man out in the family...everybody knows he is mad and is part of our family this is embarrassing...it's a shaming yet unavoidable"

One mother stated that: *"Sometimes he goes to beg for food yet there is food he refused to eat at home...he would eat without washing hands, pass urine anywhere without shame."*

The study revealed that families with a mentally ill family member were desperate. They were hopeless, distressed, frantic, and fraught. One mother who had several mentally ill family members said:

"Because of this sickness every body's' ideas appeared good and we could not refuse any...whoever visits would bring some herbs and I had no power to refuse because I was in need of a cure for my sons' diseases...at the end I decided just to become born again may be it is God who wanted me to go through this trial"

Another mother said:

"To avoid him having attacks we have to do those things he wants...he has a bicycle so we have to buy him the spare parts such that he can continue riding as he wants but this couldn't even help...sometimes at night we would ignore and assume he was safe...we would sleep but of course still thinking about him wondering how safe he is."

One sister concluded that: *"We are tired of looking after him but because he is our brother; we have nothing to do."*

Another emotion generated while living with mentally ill family members was that the family became pessimistic. Family members were cynical, glum, or unenthusiastic about the future. One mother said: *"Those young grandchildren you never know might become mad also because they have not reached that stage when the others become mad."*

Another mother said: *"We were worried all the time that he would disappear and if he escaped we would keep wondering where he was".* The mother also worried and said: *"Am worried if by bad luck I died who will care for my mentally ill child".*

Another emotion generated was that family members felt guilty about the patient's suffering. The family members expressed censure, reproach, or self-blame for suffering that the patient went through. A sister to patient said: *"We had to blame ourselves because it was our mistake not looking for him when he disappeared from home in the night...he wouldn't have been injured by the mob"*

Disappointment was another emotion generated by living with a mentally ill family member. Family members were distressed, frustrated, and regretted what was happening to them as family. A mother said:

"He doesn't know that I like him...it is difficult to love him, even if I gave something good he couldn't come back with it, he would throw it away or even destroy it...I sometimes wonder why God gave me a child just to suffer in this world...I some time feel so depressed with sorrow on my heart because I would now be getting support from all my children but it was not possible...my first son had made money and at that time he was very rich, he died two years down the road with mental illness and we lost him...he was a graduate from the university and he was also teaching in the high school...he run mad and I also lost him...can your image aren't those five?... I lost them and I attribute this loss to mental illness...Imagine all my seven children suffering from nothing but mental illness five of them dying with mental illness ...we have lost it all...children of the same age like my first born are driving good vehicles but mine died like one who had never gone to school...he could have got a good job, and a family of his own but all this has shuttered down...I would have wished my son to have his own home, a wife, a family children, and also a good job to earn money from...he would be helpful man to me but now madness spoiled him".

Another mother, whose son ended his education at lower primary, said:

"He would have studied and even got a degree... all these hopes I had are no more... he is becoming worse every day so I believe he will never be well again".

Societal responses

The study revealed that living with a mentally ill family member generated various societal responses. One of the responses was that society was callous with the families of mentally ill. The community was unsympathetic, heartless, pitiless, or insensitive to families with a mentally ill family member. One mother said:

"Nobody even comes to visit and see us for mental illness... it is considered a problem brought about by deliberate mistakes of the family that are not worthy sympathy... not even one sympathizer." A sister to the same patient said: *"Our mentally ill brother has never received sympathy from any one...church friends still*

wonder why I never attend church service and yet they are well aware that there is a mentally ill patient in my home...People in the village never considers this as an illness."

Another societal response was discrimination. The family members realized that people avoid, turn away, shun, pass up or evade the families, homes, or the sharing of commodities associated with the mentally ill family member". One sister to the patient said:

"Even people at home don't want to share plates with him.....it is known that our family suffers mental illness....we girls are discriminated because if we marry in another family we may produce children who will suffer mental illness...sometime people avoid the home because there is a mud person...if he is given a drink or food from another home, the cups/plates he is given in other families are special and not used by others... it should be old worn out such that they can be thrown away after he has gone away...all my sister and brothers now avoid my home because I am the one staying with the mentally ill brother"

Misconception about the causes of mental illness is another societal response. The family members held false impressions that mental illness is contagious, and can be caused by demons and witchcraft as one mother said:

"We thought it is traditional illness ...not treatable by western medicine ...ancestors would get annoyed if we took him to hospital...the disease was due to witch craft or traditional illness...we grow up knowing that mental illness is contagious."

One sister who took on the care of her sick brother alone said: *"My sisters thought that mental illness would be passed to her children."* Another mother thought her son had joined a bad group that was making him behave badly.

Behavioral challenges

The mentally ill family member behaved in ways that created challenges to the families. One of the challenging behaviors that the family caregivers experienced was that, the mentally ill family members are always exasperated. The family members perceived the mentally ill being annoyed, hungry, irritated, or maddened always. The patients were also infuriated and upset most of the time. This was learned from one mother, who said:

"He is ever annoyed, quarrels for anything...to him what is considered simple is taken seriously and makes react at extremes... sometimes he just keeps quiet, starts crying while spitting."

A sister to the patient said: *"He gets annoyed with no apparent reason...when interrupted he started fighting...when we stop him from shouting he becomes violent and beats anybody he comes across... he begins by refusing to take medicine then becomes violent and*

aggressive."

Behavior of the mentally ill family member was found to be intolerable. Family members described the behavior of the mentally ill family member as unbearable, unendurable or excruciating.

This was revealed as one mother said:

"She started behaving in a way that is unusual until we realized that she was mad...she started by saying someone with a long knife that is used to cut banana leaves is hunting for her to end her life so she would rather commit suicide than die of that long knife...she ran and entered some other peoples' houses up to the bed room and locks herself there... one time she woke up as I was going to work and started talking uncoordinated words like 'we are going to kill you' at this time she was not addressing anybody but just talking to self"

Another mother who experienced unusual behavior said:

"He does not accept what others tell him even if it is good for him like bathing and even washing hands before eating...he started by keeping quiet for long hours without talking to anybody ...even attempts of someone to try and talk to him would just be ignores... sometimes would pen his mouth as if whispering to someone... then laughs sometimes loudly"

One sister reported that:

"He does not want to bathe or even brush his teeth... Staying with him is hard since he is always dirty, he does not care but we have nothing to do...he could not explain what happened but smile while facing empty space...he removes the dressings and even put dirt in the wounds as blood spilled all over the place from his wound...carries hands on the head when he is given food and never eats it. ...he eats rotten food and refuses good food cooked at home"

An aunt whose mentally ill family member broke down while at school informed that:

"He would go to school and then gets out of class and wanders away.... teachers tried to stop him from that behavior and he stopped going out class but could sit in class without doing the class work....he could instead spoil his books by drawings like those of lower primary school child...after leaving school he would never reach home, he could not bath or change clothes and would sleep in the trading Centre"

The many bizarre complaints of the mentally ill family member caused challenges to the families. The family members realized that the mentally ill patients had complaints that were weird, wacky, unusual, strange, and sometimes peculiar. A sister to a mentally ill brother reported her brother said: *"Snakes enter my anus, move through the spine cord and eat my brain at night...this makes me fail to sleep."*

The patients' behaviors were also found to be sadistic. The family members found the mentally ill being destructive, caustic, vicious, stern, furious, and brutal. The patients were also found to be ferocious, and fierce.

One mother said: *"He destroyed things in the house...opened and left the taps of water flowing, throw plates through the window and broke thermo flask...the worst day was when he wanted to burn everything in the house...he gathered most of the things in the house into the living room with an intention to burn them...he does things sometimes aimlessly even when they have serious consequences like death...he one time hit the cat to death"*

One sister said:

"He starts attacking any body and destroying peoples' property like he hit a wind screen of a moving vehicle...if he was left alone he would destroy things at home or not to mind if anything was going wrong...if he is aware of the place where I kept money he would pick it and spend nights drinking and buy people alcohol...he spoils things in the house and when stopped he turns to something else without showing that he did something bad or he is sorry"

Another behavior was that patients would vanish from home. The patients could disappear, run away, flee, take off, or escape from home time to time. A mother, who looked disgusted, said:

"He jumped out over the wall fence and went to the nearby shop where he just picked merchandise without paying...he likes moving away from home a lot...then commits offenses wherever he goes." One sister said: *"At one time the patient was fair but would lose senses and start wandering around among the relative ... she would start shouting and even make attempts to run away from home."* She added that: *"He disappears especially when he gets money ...he sometimes escapes away from home and by the time I am aware that he is gone he has boarded a vehicle and very far away even when he does not have money"*. Another mother said: *"He wanders away from home and we have always looked for him many times including late in the night only to find him in abandoned houses with a lot of rubbish around him."* Another behavior was refusal to take medication and the family members would plead with the patient. Family members had to ask, beseech, press or appeal with the patient in order for them to take their medication.

One mother said: *"He would only take the medication regularly within a few weeks after discharge then he would stop and we have to appeal to him to take it...we have just to beg him to take the medicine because if he did not take it he would be a problem for everybody."* One sister said, *"He used to care for himself but now you have to tell him to do everything like washing clothes, and asking him to take medicine."*

Helpful circumstances

While caring for the patient families with mentally ill family members found some circumstances helpful to their living situation. Hospitalization was one of them and would give

liberty to the caring family members. The family members got freedom, reprieve, or respite when their mentally ill family member was admitted in a mental hospital. One mother said: *"When he is in hospital I find life easy, no worry, no panic...I wouldn't want him to be permanently in the hospital because he is my son but when he is away I feel relieved."*

One sister stated:

"Until we brought him to hospital that we got some peace at home...thanks to police which arrested him and brought him to hospital as he was obstructing traffic...we are happy he is in hospital because we are free of worries at home and we know he is safe on treatment"

Another mother who appreciated hospitalization said: *"We had given up for him because we could not keep him home until someone suggested to us to bring him to hospital... when he is in hospital we really got relief up to now...we don't worry so much because we are sure he is in hospital and safe."*

Hospital medication was also found to be helpful. The family members reported medication received from hospital being useful, handy or versatile. One mother said:

"When he takes the medication he becomes well and we have not got many problems with medication because they give us free medicine from the hospital and it has really helped... when he takes time without taking the medicine he becomes destructive...when he takes the medicine he sleeps well up to morning but when he doesn't he will move in the house throughout the night."

Mental illness is a cohesive factor among the parents and some social groups. The family members living with the mentally ill attain intimacy or closeness to the church, counselors and among themselves as members of the same family. One mother revealed that: *"The church is now closer to my family because of having this patient in the family."* A sister to the patient said: *"Through the experience with my brother's illness I have learnt to be more loving and caring than before he become ill... I now had empathy and really feeling for some body... I have also known another person can genuinely be in need of another person for help."*

Another mother said:

"The benefit we have got also is that we have been able to get counselors to talk to us because they realized caring in such a big burden to us...as we request for prayers for our brother they also preach to us and even counsel us about what we are going through...we care for the patient in turns as a sign of togetherness and being able to share the burden care"

There was good rapport between families with a mentally ill family member and their neighbors because neighbors were considerate, kind, accepting, or indulgent with the mentally ill patient. A mother said:

"Now our neighbors know and they don't conflict with him or fight him...they always call us when he starts

disturbing...we have been in good relationship with our neighbors; they sympathize with us having a problem of the mentally ill children in our family...even if my mentally ill children did some wrong they would say those are sick children you can't blame them"

DISCUSSION

Female caregivers were the majority of the care givers seen in the hospital at any one moment. This is similar to Howard (1998) who realized that mothers "carried the major load" and fathers were involved in providing finances for living and medical expenses; direct monitoring of the child during times of crisis and following hospitalization; and assisting in decisions about medical treatment, education, work, and housing. In the same line, Nystrom, (2004) stated that; as it was often seen; mothers were too deeply concerned with the patient's behavior and could view their child's actions critically.

Living with the mentally ill family member devastated family revenue. The family income, proceeds, earnings, and profits are used to pay for the expenses associated with caring for the mentally ill family member. Similarly, Leticia de Oliveria et al. (2008) found that mental illness imposed a large financial burden to the families with mentally ill patients.

Contrary to the above, however, Cohen, Colantonio and Vernich (2002) studied the positive aspects of care giving and found that majority (70%) of participants reported positive feelings in regard to caring responsibilities. The specific positive aspects they mentioned were companionship and a sense of it being fulfilling and rewarding. Others mentioned a sense of duty and obligation as well as enjoyment.

A majority of family members, after realizing that their relative was mentally ill, sought help from a folk healer, but, noticed that the patient's situation deteriorated after a few months.

Hospitalization of the mentally ill family member meant liberty and freedom for caring family members. The family members enjoyed freedom, relieve, or respite when their mentally ill family member was admitted to a mental hospital. The family members preferred their mentally ill family members to be admitted to hospital rather than caring for them at home. This fact poses a dilemma for the mental health care system in Uganda which is currently advocating for a reduction in the number of admissions to mental hospitals while encouraging treatment of patients from the community.

Implications to Mental Health Nursing

While mental health nursing is advocating minimizing hospital admissions, family members consider admission of the mentally ill family member as liberty to the family

and a break from the routine, and the monotonous and tiresome collection of medication from the hospital.

Mental health nursing has to adopt a comprehensive approach to manage patients' illnesses and also attend to the stressful consequences the family members experience as a result of living with and caring for a mentally ill family member.

CONCLUSIONS

The study revealed that living with a mentally ill family member resulted in depriving of their social life, had financial ramifications, brought on unpleasant feelings, and led to monotonous and tedious collecting of free medication. The mentally ill individual was a prime focus in the family and family members had to be vigilant.

Living with a mentally ill family member generated emotions and feelings among family members such as misery, embarrassment, disparity, and pessimism about the patients suffering. Caring family members also expressed disappointment and facing a dilemma.

There were societal responses as a result of living with a mentally ill family member. These responses were societal callousness, families being discriminated against, as well as the public holding misconceptions about mental illness.

The mentally ill family members behaved in ways that were perceived as challenging by family members. They perceived the mentally ill as exasperated always, having bizarre complaints, as well as behaving sadistically and intolerably.

There were circumstances that family members found to be helpful, like hospitalization of the mentally ill family member, use of hospital medication and neighbors who tolerated the mentally ill family member. Mental illness at times also worked as a cohesive factor.

Living with a mentally ill family member was considered a prime issue that became intolerable for the affected families.

RECOMMENDATIONS

There is need for the Government and non-government organizations to instate programs to screen mentally ill members of the community since many are taken to traditional healers, or go completely without treatment until they conflict with society in such a way that they require hospitalization. Such programs will not only help in the screening but also in the early detection and prevention of mental illness.

After the hospital admission and discharge, there is need to follow up on patients in the community. This is because many family members emphasized the difficulty of the monotonous collection of medication for the patient from the hospital. This follow up could help on the

escalating number of patients defaulting to treatment, and relapses.

Counseling programs that emphasize the care of the mentally ill and the family members should be put in place. This will help them cope with living with the mentally ill family member that they considered as the 'prime issue'. There is need for micro financing for families with mentally ill family members. There is also need for income generating activities at home since income generating activities outside the home often cannot be performed. Health workers in mental health units should also communicate with family members about their experiences as carers for mentally ill family members. This will help health workers recognize the challenges faced while living the mentally ill family member at home.

REFERENCES

- Ayres L (2000). Narrative of family care giving: Four story types. *Research in nursing and health* 23:359-371.
- Browne G, Hemsley M (2010). Housing and living with a mental illness: Exploring carers' views. *Int. J. Mental Health Nursing*, 19:22–29.
- Cohen AC, Colantonio A, Vernich L (2002). Positive aspects of care giving: Rounding out the carer experience. *Int. J. Geriatric psychiatry*, 17:184-188.
- Colaizzi PF (1978). Psychological research as the phenomenologist views it. In Polit F., D. and Beck TC (2008). *Nursing research; Generating and assessing evidence for nursing practice* (8th ed.) pp. 519-520 Philadelphia: Lippincott Williams and Wilkins.
- Doornbos MM (2001). Family care giving for young adults with serious and persistent mental illness. *J. family nursing*, 7:328-344.
- Goodwin V, Chappell B (2007a). Consumer and carer participation in mental health care: The carer's Perspective: Part 1: The importance of respect and collaboration. *Issues in Mental Health Nursing*, 28:607–623.
- Goodwin V, Chappell B (2007b). Consumer and carer participation in mental health care: The care's Perspective: Part 2: Barriers to effective and genuine participation. *Issues in Mental Health Nursing*, 28:625-638.
- Howard BP (1998). The experience of fathers of adult children with schizophrenia. *Issues in Mental Health Nursing*, 19:399- 413.
- Huang XY, Sun, FK, Yen WJ, Fu CM (2008). The coping experiences of carers who live with someone who has schizophrenia. *J. Clin. Nursing* 17:817–826
- Leticia de Oliveria B, Schwarts E, Prado K (2008). Stress on families living with the reality of mental disorder. *Acta Paul Enferm*; 21:588-594.
- McEwen M, Wills EM (2007). *Theoretical basis for nursing* (2nd ed.). Philadelphia: Lippincott Williams and Wilkins.
- Muhlbauer S (2008). Caregiver needs Regarding Symptom Attention in severe and persistent mental illness. *Perspective in psychiatric care*; 44(2):99-109.
- Neufeldt V, Guralnik DB (1998). *Webster's New world Dictionary of American English*, New York City, MacMillan.
- Nystrom M, Svensson H (2004). Lived experiences of being a father of an adult child with schizophrenia. *Issues in Mental Health Nursing*, 25:363–380.
- Ostman M (2004). Family burden and participation in care: Differences between relatives of patients admitted to psychiatric care for the first time and relatives of re-admitted patients. *J. Psychiatric and Mental Health Nursing* 11:608–613.
- Pickett-Schenk AS (2003). Family Education and Support: Just for women only. *Psychiatric Rehabilitation J.* 27:131-139.
- Polit FD, Beck TC (2008). *Nursing research; Generating and assessing evidence for nursing practice*. (8th ed.) Philadelphia, Lippincott Williams and Wilkins.
- Rose L, Mallinson RK, Walton-Moss BA (2003). Families of patient with mental illness revised their Ideas of what it means of what to live a 'normal' life. *British medical association* 35:19-28.
- Saillard KE (2009). Psychiatrist view toward people with mental illness and their recommendations. *Turkish Journal of Psychiatry*; pp. 1-10.
- Stengler-Wenzke K, Trosbach J, Dietrich S, Angermeyer MC (2004). Coping strategies used by the relatives of people with obsessive–compulsive disorder. *J. Advanced Nursing* 48:35–42.
- Stern S, Doolan M, Staples E, Szmukler GL, Epistler I (1999). Narrative insights into the experience of family members caring for a relative diagnosed with a serious mental illness; *ProQuest Psychol. J.* 38: 353.
- Walton-Moss B, Gerson L, Rose L (2005). Effects of mental illness on the quality of life. *Issues in Mental Health Nursing*, 26:627-642
- Ward-Griffin C, Schofield R, Coatsworth- Puspoky R (2005). Canadian families caring for members with mental illness: A vicious cycle. *J. Family Nursing*, 11:140-161.
- Wynaden D, Orb A (2005). Impact of patient confidentiality on carers of people who have a mental disorder *International Journal of Mental Health nursing* 14:166–171
- Yip KS (2005). Family Care giving Of Clients with Mental Illness in the People's Republic of China). *Int. J. Psychosoc. Rehabilitation* 10:27-33.