

A Qualitative Approach to Study Differences in Well-Being and Experiences of Male & Female Caregivers Living with Mentally Disturbed Patients

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Abstract: The present study was conducted to investigate the experiences and well-being (WB) of male and female caregivers of psychological disorder patients. The purpose of this study was to examine what kind of experiences both male and female caregivers faced and how these experiences influenced on their well-being (WB). For the present study, qualitative approach was used. For this, participant (N=10) were selected through purposive sampling. The researcher conducted semi-structured interview to gather in depth information from participants. After data collection, all interviews were transcribed and analyzed by using Interpretative phenomenological Analysis (IPA). The researcher extracted seven major themes from interviews, *health practices, accountabilities and duties, turning to religion, social stigma, life situations, and gender disparities*. Results indicate that having any of the family member with a psychological disorder can be very distressing. Furthermore it was reported that both male and female caretakers writhed with misery, burden, symptomatology of patients, along with adverse influence on their family as a unit. On the other hand results indicated that life and well-being (WB) of the females are more affected if any of the member is suffering from any sort of the mental disorder (MD), they become victims of the violence and face problems in their marriages on the other side male face problem in moving society and having less job facilities.

Key words: *psychological disorder, caregiver, gender disparities, well-being (WB).*

Introduction

Studies have shown that family caregivers perform a vital role in process of rehabilitation and treatment of people with mental disorder (MD) (Dixon et al., 2001). According to APA (2015) *caregiver*, is defined as an individual who tends to a person's needs and provides assistance those who are not completely independent, like a baby or an ill adult. In short an individual who performs majority of work is known as **primary caregiver**. Caregiver may be any person like father, mother, daughter, sister, son or spouse.

When family members provide care to MI patients they perform multiple roles like providing care day-to-day, supervision of medications, accompanying the patient to hospital and upkeep the financial necessities. They also have to tolerate patient's behavioral disturbances. In short, the family caretakers experience substantial amount of burden and stress, and require assistance help in dealing with it (Chadda, 2014). The experience of care providers encompasses concern, distress, stigmatization, embarrassment, and guiltiness (Tull et al., 2007; Ogilvie et al., 2005).

Wellbeing (WB) is an essential construct to measure the caregiving experience as it shows both strengths based perception and harmful result of caregiving. This constructs is viewed as complicated, multifaceted phenomena that include both subjective and objective dimensions (George, 1994). WB refers to the capability of discovering all abilities of a person which are derived from harmonizing amid positive and negative emotions and satisfaction with life (Durayappah, 2011).

As a result of providing care, carers face many difficulties, among them some of the highlighted ones are facing distress emotionally and psychologically, decline in social contacting,

Ansa Talib: A Qualitative Approach to Study Differences in Well-Being and Experiences of Male & Female Caregivers Living with Mentally Disturbed Patients

monetary difficulties, along with reporting low satisfaction in life, reduced mental and physical health (Ae-Ngibise et al., 2015). The long-lasting stress and day to day hassles lead to intense burden subjectively and objectively for caregivers of severe MI patients (Saunders, 2003). Preceding studies have reported that carers of relative with various MI go through high level of mental distress, severe monetary and socio-psychological difficulties along with day to day life difficulties which results in low QOL (Angermeyer et al., 2006). The burden of care badly affected on the quality of life, physical condition and performance of the caregiver (Yamazaki et al., 2005). The experience of caregiver shows detrimental outcomes like high level of stress, burden and physical and psychological health problem. A research reported that higher psychological well-being of care givers is associated with less care giver burden and high quality of life (Lethin et al., 2017). A lot of barrier negatively affect the caregiving person like huge number of burden, lack of professionals, and lack of support from mental health doctors. Social network effects on the quality of life of the caregiver particularly when caregiver treats the ill patient of their family (Biegel et al., 1994). The demands of caregiving like paying for psychiatric treatment, supervision of the patient, dealing with social stigma that connected is with mental illness leads to emotional distress among caregiver (McDonell et al., 2003).

There are abundant of studies performed on gender disparity of carers for older adults, the study establishes that females attend to and offer more time for caring and involve in more responsibilities as compared to men (Calasanti & Bowen, 2006). Male carers have been categorized as being more instrumental than female, focusing on certain responsibilities, whereas females are subject to emotive tasks, maintenance of individualities and relations (Carroll & Campbell, 2008). Researchers have reported that female carers face more burden as compared to their counterparts (Garlo et al., 2010; Kim et al., 2012) and low self-esteem (Kim et al., 2007),

even though some researches have reported no gender disparity in burden (Rosdinom et al., 2013) or distress or depression (Mohamed et al., 2010).

Healthiness of the care receiver could refer to numerous characteristics of their condition, like, decline in performing daily living activities and instrumental daily living activities (Gallagher et al., 2011; Kim et al., 2012); decline in cognition (Ryan et al., 2010) and disturbances in behavior like being agitated, aggressive, anxious, irritable, hallucination, delusional, apathy, disinhibition, and motor over-activity (Cheng et al., 2013; Leroi et al., 2012). How care giving influences on the carer's well-being could be described in reference to outer resources. Lacking informal support, inability in taking breaks when required (Goldsworthy & Knowles, 2008), poor relation quality with the care receiver (Goldsworthy & Knowles, 2008), and lacking in receiving formal services (Zarit et al., 2011) could be co-related to more pressure in carers. Internal resources of care providers also influence on their well-being and cause distress, such as seclusion/social seclusion, lacking in secondary intrapsychic strong points like capability and inner power (Pearlin et al., 1990), feeling of underappreciation, and one's health (Chappell et al., 2014). Sociodemographic characteristics of caregiver are of significance as well. Less monetary resources whether in terms of pay or societal class (Robinson et al., 2009), less qualification (Navaie-Waliser et al., 2002) living with care receiver (Kim et al., 2012), and young age (Andren & Elmstahl, 2007), every so often all these factors have been highlighted as to lowering the well-being of caregiver.

In developed countries the part played by a caregiver in the management of patient with severe health issues is well acknowledged (Pompili et al., 2014). For past periods, most of the mental health professionals and researchers have focused most of their efforts and time on people residing with MI patients with precise concentration on causativeness and symptomatology (Flisher et al., 2007). However, now it is the need of current time, mainly in developing countries,

Ansa Talib: A Qualitative Approach to Study Differences in Well-Being and Experiences of Male & Female Caregivers Living with Mentally Disturbed Patients

that the experiences of the care providers living with MI patients should be focused as well, because here the health care systems for the management of MI patients and their care providers are deficient (Flisher et. al., 2007; Ae-Ngibise et. al., 2010). In developing countries the in availability of appropriate health systems influences on QOL, thus deteriorating the diagnosis and management of mental health issues, along with documentation of disable members in community with MIs and worsening the burdens of caregiver. A study reported that (MI) has substantial negative outcomes on patient's and caregiver's quality of life (QOL) predominantly in countries with low- income and middle-income (Jungbauer et al., 2004).

System for social support does not exist, especially for illnesses like MI, which is generally denounced. As a result care providers of MI patients are left with no choice but to bear their need for emotional support, physical support, monetary and spiritual needs alone (Johnson, 2015).

Although wellbeing of care providers is challenged while he/she is looking after family member with prolonged MI (Siddiqui & Khalid, 2019). Results of another research suggested that the caring burden that is experienced by family providing care to ageing patients has a negative impact on their emotional, physical and mental health that in turn influences adversely on their QOL as well as their subjective well-being (Shakeel et al., 2015). That is why many professionals of mental health frequently view close relatives of MI patients as individuals of provision for the reason that they act as informers of patients along with providing therapy at home (Hasui et al., 2002).

Apart from that relatives who agree to take care of MI patients are effected in both social and psychological aspects (Caqueo-Urizar et al., 2009). A study described that wellbeing of care providing relatives is influenced by severe MI patients. It also pointed out the significance of

providing support and counseling services to caregivers so that it might help in reducing their burden of care (Siddiqui & Khalid, 2019). From this we can conclude that optimal psychological and social state is very essential for family members providing care to MI patients. A study pointed out that children of MI parents are member of special risk group that is relevant to the development of MI. in addition they also pointed out that up to half of the adolescents who consult for psychiatric services, live with MI parent (Mattejat & Remschmidt, 2008). Larson and Corrigan, (2008) reported in their study that reduction in working of even one member of family increases burden of others resulting in development of serious attitude towards the patient from other members. Condemnation of any sort can result in deterioration of patient's illness or in some case scenario development of overwhelm feelings in family members because of disrupting behavior of patient (Ssebunnya et al., 2009).

Manjula, and Raguram (2009) also reported that older children of MI parents reported that during their childhood period they had experienced many troublesome events like family unsteadiness, parental discord and study discontinuation. Several among them, despite being strong, reported burden and lack of support (Herbert et al., 2013). Female care providers face many difficulties in their day to day life especially when one of the family members is MI patient. No doubt male caregiver also fulfills their duties and give attention of their family but a study has established that females attend to and offer more time for caring and involve in more responsibilities as compared to men (Calasanti & Bowen, 2006).

In short, it is very essential that experiences of caregiver in providing care to MI relatives should be understood in a detailed manner since this will aid the psychiatric professionals and community service providers to have a better understanding of needs of caregivers when caregiver

Ansa Talib: A Qualitative Approach to Study Differences in Well-Being and Experiences of Male & Female Caregivers Living with Mentally Disturbed Patients

directed interventions are planned. Current research focuses on exploring the effects of caring for MI patients on caregiver's WB and investigating gender disparity in caring.

Method

For the present study qualitative research design was used. Qualitative method was used to get the in-depth information and understanding.

Participant

Purposive sampling technique was used for the data collection. **10** participants were selected for the interviews i.e. 5 females and 5 males respectively living with patients of MI. The family caregivers (informants), age ranged between 18 to 40 years. Most of the informants had primary level and a few had secondary level education. Recruited informants were caring for ill relatives with different types of mental illness including schizophrenia, bipolar disorders, substance-related disorder-alcoholism, drug abuse and epilepsy with psychosis. The duration of patient's illness ranged from 9 months to 20 years. Five informants were men and nine were female. Female informants were housewives and among male informants 2 were daily wagers and 3 had small petty business.

Instrument

Tool for the data collection was self-constructed questionnaire.

1. How male and female caregivers survived while taking care of patient with psychological disorder?
2. Differences among male and female caregiver's experiences while attending the patient with psychological disorder?
3. How their health suffers in these situations?
4. Is there life turned towards religion, or they become nearer to religion in these type of situations?
5. What kind of social and family circumstances they faced?

Procedure

Firstly researcher prepared the interview protocol, it was used to cover all the objectives of the research. Researcher met to the participants through informal way. Before conducting the interview participants were assured about the confidentiality and took permission of audio recording of the interview. After then rapport was built with the participants, probing questions were also asked by the researcher for getting the exact information. After the interviews, all interviews were transcribed and analyzed through the interpretative phenomenological Analysis (IPA).

Mode of Analysis

Ansa Talib: A Qualitative Approach to Study Differences in Well-Being and Experiences of Male & Female Caregivers Living with Mentally Disturbed Patients

The interpretative phenomenological analysis (IPA) is a qualitative research approach whose main objective and essence is the exploration of 'lived experiences' of participants of research and allows them to narrate their findings through 'lived experiences'. Smith et al. (2009), known as most acknowledged theorists of modern-day minds stated that this qualitative research approach is dedicated to examining in what way people make sense regarding their major experiences of life. In this approach the researcher first read through the responses of interview on order to classify common themes i.e. searching for repeated phrases or words from the responses of participants. In the next step the researcher chunked down the words or phrases into fewer words so that the core essence of what the participant were trying express could be tracked down. And in last step the researcher described the composite description of phenomena in short the essence of experiences of participants.

Ethical Consideration

Ethical approval was acquired from administrative department of DHQ hospital psychiatry ward, Faisalabad. Further permissions were acquired from Medical Officer in charge of psychiatry ward. Afore commencing of interview, the informants were briefed in detail regarding the process of data collection. Each participant was fully briefed concerning the nature of study and they decided to participate willingly in the study. Hard copy of consent form was read and signed by the informer. Informers who were unable to put pen to paper were asked for verbal consent. Confidentiality of all caregivers was assured by maintaining anonymity. Liberty of withdrawing at any time from the study was guaranteed.

Result

Themes Identified

Six major themes emerged out of data. Major theme consisted of various sub-themes which are explained briefly within every major theme in the table below.

Table 1

Interpretative Phenomenological Analysis of semi-structured interviews

Major Themes	Connecting Themes	Initial Themes	
		Male	Female
Health practices	Mental/Psychological Health	Stress	Anxiety for future stress
		Frustration	Frustration
Accountabilities & duties	Mental/Psychological Health	Angriness	Angriness
		Feelings/ thoughts of Hopelessness	Feelings/ thoughts of Hopelessness
		Mentally disturbed	Mentally disturbed
		Sad	Sad
			Don't take interests in daily routine
	Physical Health		Sleep disturbance
			Silent all the time
			Negative attitude about family
		Dizziness	Dizziness
		Headache	Monitor fever and blood pressure
Accountabilities & duties	Caring & flexible	Shoulder pain	Vomiting
			Headache
			Fever
			Pain in eyes
			Fainted
	Caring & flexible		Muscle Cramp
			Required Attention
			Responsibility
		Tiredness	Care taker required attention
		Breadwinner	Over responsibilities
		Tiredness	

		Struggle/ hardworking People make fool Marriage bond affected Social burden	Struggle/ hardworking Household chores Criticism by people People make fool Social burden Marriage bond affected Difficult to face society
		<u>Criticism by people</u>	Domestic responsibility Social pressure
Societal stigma	Social Involvement	People perceive we are not good enough Difficulty in social mobility No social support	People perceive we are not good enough Difficulty in social mobility No social support Lack of social attention
Turning to Religion	Religious Forte	Prayers Religious Strengthen Hope Faith Peer pressure to take taweez	Attentiveness towards shrines Attractiveness towards Aulis of Allah Prayer Faith Religion strengthens Hope Demands a lot of things from Allah Handling with spirituality God Jesus will take burden of our sins Ask for sins forgiveness
Life situation	Social life circumstances	Lack of social attention	Society consider mental illness as bad luck Accept negatively
	Family life condition	Marital life disturbed Sibling's relationship negative	Accept negatively Home disturb

Ansa Talib: A Qualitative Approach to Study Differences in Well-Being and Experiences of Male & Female Caregivers Living with Mentally Disturbed Patients

	Home disturb Decision making not possible Family life disturbed Financial crisis	Not normally spend time Financial crisis Sibling's relationship negative Decision making not possible Marital life disturbed Parents both disturb Family history
Reactions and emotional state	Hopeless and helpless No happiness No hope of getting good luck Dark future Happiness far away	Inferiority complex Hopeless and helpless Feel jealousy Other people are good we are bad No happiness No hope of getting good luck Dark future Happiness far away Suicidal thoughts
Gender disparities	Negative repute effects daughters life Being male difficulty in career	male always tortured their wives more societal pressure on wives females consider as submissive male always tortured their wives Domestic violence Male domination

Health Practices. This major theme encompassed both physical and psychological aspects of male and female caregivers. In *Mental/psychological health* sub-theme it was found that female experience anxiety regarding their future, along with stress and frustration due to their current condition. They also experience anger and feelings and thoughts of hopelessness as mentioned in the literature that the MI patients often engage in disruptive behavior that is not only disturbing for the care taker but also a main source of emotional outbreak among them. Also it was found that female tend to feel more sad and don't take interests in daily routine. Sleep disturbances and negative attitude towards family as way to take out their frustration was also reported along with being silent all the time. In contrast to female, male caregiver reported stress, frustration feelings of anger and thoughts of hopelessness along with mentally disturbance and being sad. The results also reported that as compared to male female experience more difficulty in maintaining their psychical and emotional health as compared to male.

The next sub-theme was *Physical Health*. It was found that female experience dizziness, along with fever, blood pressure, vomiting, headache, pain in eyes and muscle cramps because of insufficient sleep and diet. Male caregiver reported dizziness, headache and pain in shoulders due to dark future.

Accountabilities and duties. The sub-theme of this major theme was *Caring & flexible*. Female caregiver reported that MI patients required constant attention so that they may not hurt themselves. Along with that they reported that their responsibilities doubled since they had to tend the patients and provides for family as well i.e. making food, cleaning house and sending their children and husband to school and office. They also reported that care taking required loads of energy which eventually led to exhaustion and tiredness. In comparison to female, male caregiver reported that MI patients required attention. They also reported that their responsibilities had increased due the fact that they had to provide for family and for the patient. They also reported that their caretaking duties had increased which caused them tiredness.

Turning to religion. *Religious Forte* was subtheme of this major theme. Female caregiver reported that after having a MI patient in family their inclination towards religion had increased tremendously. They reported that they have become attentiveness towards visiting shrines, are attracted towards Aulis Allah. Their duration of prayers had increased. Also their feelings of hopes and faith have also strengthened that one day things will get normal. Some females reported that they had experienced peer pressure to take taweez for MI patients and after facing that pressure that had started to visit shrines and making more demands from Allah. They further reported that along with medical treatment they are handling their current situation with spirituality. Few female caregivers reported that the situation they are facing now is due to their sins and they are seeking forgiveness from Allah so that their situation can come to normal. As mentioned in the literature that in Asian countries there is a trend to seek spiritual help first instead of medical treatment, the same trend has been found here as well. Male caregiver also reported that their inclination towards religious has increased. They offer prayer have high hope and faith that things will get normal in due course. They also reported facing peer pressure to take taweez.

Social stigma. This major theme had following subtheme, *Social Involvement*. Here female caregiver reported that they are struggling in their present condition. They have to perform a lot work along with facing criticism from society. They also experience social burden from not only outsiders but from within their family and that they have difficulty in facing society. People take them for fool. Female also reported that their marriage bond is also effected due this major fact. Male caregiver also reported struggles, criticisms from people and social burden. They also reported that current scenario is affecting their marriage life.

Life situation. This theme had following subthemes, *Social life circumstances*, *Family life condition* and *Reactions and emotional state*. In the first sub theme the female caregiver reported that people perceive we are not good enough. They also reported having difficulty in moving and with the society. They further reported that they have no social support and lack in social attention from society. The female caregiver reported that people in our society consider mental illness as bad luck and consider it negatively. Male caregiver reported that people perceive them as not good enough to hang out with. They further reported difficulty in social mobility and lack of social support and social attention from society. As for *family life condition* female caregiver, reported disturbance in management of house hold activities, inability to spend time like normal family, experiencing financial crisis and negative relation with siblings. They further reported that they had difficulty in making decisions along with disturbance in family and marital life. Female caregiver further reported that their family had a history of mental illness. Male caregiver reported disturbances in home and family and marital life along with monetary challenges, negative relation with siblings along with inability to make decision.

In *Reactions and emotional state* subtheme female caregiver reported inferiority complex, feelings of hopelessness and helplessness, feelings of jealousy towards other people, suicidal thoughts, no happiness, no hope for happiness in future. Male caregiver reported feelings of hopelessness and helplessness and no hope for future of or finding happiness.

Gender disparities. In this major subtheme female caregiver reported being tortured by their husbands, experiencing domestic violence due to male domination and societal pressure. Male caregiver however reported that negative repute effected their daughter's life. Having difficulty in finding job due to their gender because females are more preferred than males.

Discussion

Ansa Talib: A Qualitative Approach to Study Differences in Well-Being and Experiences of Male & Female Caregivers Living with Mentally Disturbed Patients

The present study was conducted to know about the experiences and coping behavior of male and female care giver having mental disorder (MD) any family member. For this purpose 10 semi-structured interviews were conducted from five female and five male. Interpretative Phenomenological Analysis was used and seven major themes were extracted after the analysis.

First major theme extracted from the transcribed interview is “Health practices”, it includes different common themes which are about the psychological and physical health problems. Respondents said that their loved one most of the time feel anxiety, stress, and frustration, hopeless, blood pressure, dizziness, fever etc. As families have accepted a greater amount of the guardian part for individuals with serious mental disorder, abnormal amounts of mental trouble among parental figures have been archived. Research on guardian parental information (Cook, 1988) demonstrated that moms indicated altogether more quantifiable passionate trouble (uneasiness, depression, fear, enthusiastic channel) than did fathers. It was accounted for that females' practices and contemplations were affected by their essential part as child overseers, consequently bringing about a more prominent passionate interest in the care giving parts.

One of the female (F3) participant responded on the health issues that

“My younger sister is suffering from Depression. We know that it is only due to the side effects of typhoid, for a long time almost three months she feels temperature but she ignored. We started treatment but due to complications of fever she suffered in Depression”

On the other hand male participant (M4) said that *“My mother takes tension she is taking medicines of high BP, headache and always in the state of alertness”*

Tension might be expanded by behavioral issues of patients who can't be effectively overseen on a predictable basis Anxiety is connected with despondency, stress, and physical sick wellbeing. If any of the family member is suffering from the mental disorder whole family got disturb due to that person and always remain in the state of depression and stress, it become hard

for the family member to fulfil their daily routine work. For female it become difficult to complete their house hold chores and for male they cannot concentrate on their office work just because of this mentally disturbed family member needs more intensive care, love and time form the family. The incidence with which behavioral disturbance influences are showed by the patient has been distinguished as the most grounded indicator of care giver trouble and assumes a huge part in the guardian's choice to organize the patient.

Previous literature by the Calhoun et al. (2002) on the caregivers burden and psychological disturb partner, results indicated the patient experience a lot of health issues and care giving becomes burden due to the mental disturbance of the partners.

Next major theme is "Accountabilities & duties" it includes several different initial themes like attention, responsibilities, care, and flexible behavior. Caring to somebody with a mental issue can influence the progression of a family. It takes up the greater part of the careers' opportunity and vitality. The family's obligation in giving consideration to individuals with mental issue has expanded in the previous three decades. This has been mostly because of a pattern towards group care and the de-regulation of psychiatric patients Berkshire (2007). The change of the everyday consideration of individuals with mental issue to relatives. Up to 90% of individuals with mental issue live with relatives who give them long haul down to earth and enthusiastic support.

Caregiving burden increases as a result of more contact with patient and when patients live with their families. Strong affiliations have been noted between guardians' apparent wellbeing and feeling of intelligence, balanced for age and relationship Andren and Elmstah (2008).

One female participant (F1) said that:

"I am ignoring my family, my children are in classes, I can't spare them. My husband's job is in a mill and sometime his nightshifts timings are awkward, usually he came back on 4o clock morning. We are supporting her with our best insha Allah she will be better soon. She is attached with me".

Ansa Talib: A Qualitative Approach to Study Differences in Well-Being and Experiences of Male & Female Caregivers Living with Mentally Disturbed Patients

One of the female participant (F2) said about his husband *“I am thinking seriously about my present life, I should be separate from him why I take too tension for him .my in-laws are not taking any responsibility”*.

Male respondent (M5) said about his son

“I am in tension what will happen? How he will manage himself? I don’t know his brothers and sisters will help him or not. I am old, I can’t support him financially, and I can’t do nothing for him”.

The family guardians hold on for the behavioral unsettling influences of the sick relatives and once in a while can likewise be an objective of the patient's damaging or aggressive conduct. They need to let go of their social and relaxation exercises, and need to take leave from their occupations. Also, they need to meet the monetary requirements for household other than meeting the treatment costs. The persistent anxiety of caregiving may antagonistically influence the physical and emotional wellness of the care givers.

As indicated by Rolland (1994), in an sever issue, for example, serious emotional sickness, there is expanding strain on family parental figures as an aftereffect of fatigue and the nonstop expansion of new caregiving undertakings over the long run. The family is dependably "available to come back to work" to adapt to the everyday emergencies of extreme emotional sickness. On the other hand results are also supported by the literature of Horwitz and Reinhard (1995), who interviewed 163 guardians and siblings of extreme mental disorder, found that the conception of burden is a consequence of managing troublesome practices and giving involved and obsessive help.

Third major theme is “societal stigma” it about the societal pressures faced by the individuals due to the family member going through the any sort of mental disorder as in our society people criticize more than helping and supporting the people going through any sort of tough situation specially is any member of the family having any sort of mental disorder relatives and other people give wrong suggestion. On the other hand children feel ashamed to meet individuals and stay away from making relation with the new people. In the happening that guardians are confronting, it gets troublesome for the youngsters to adapt, everybody in the family demonstrate empathic feelings before them and give distinctive recommendations then again behind them condemn them, call as social problem and disgrace for the family. In this kind of the circumstance it get to be troublesome for the youngsters to move in the general public, individuals even don't care to meet them so warmly and they need to improve battle to get a position in the society.

One of the female participant (F5) said that

“No doubt it is too difficult to face society because you know in our society physical illness is acceptable but mental illness looks like a bad luck, or you can say accept negatively”.

Male participant (M3) said that

“Criticism, yes off course but where we are living at that time all people are sure that she is under control of some bad evil”.

The caregivers constantly feel that the patients are not accepted by the society and face a sense of isolation from the rest of society. The father of a young man (M2) said, *“People stop coming to the house. Even close relatives are reluctant to come.”*

A related statement from the father (M4) of a young unmarried woman with schizophrenia was, *“The family has to hide the disease because she is unmarried. If we tell anyone, we will face difficulty in finding a suitable”.*

Ansa Talib: A Qualitative Approach to Study Differences in Well-Being and Experiences of Male & Female Caregivers Living with Mentally Disturbed Patients

A few explanations by the respondents as given above are plainly deceptive of the disgrace, social separation and partiality experienced, even by the guardians of persons with emotional sickness. Subsequently, it is the patient, as well as the entire family, which confronts this issue. Guardians by and large felt that society does not sympathize with persons with emotional sickness, and needs comprehension of their constraints and issues. A man with emotional sickness regularly stays overlooked, is as often as possible rebuked for his or her issues, and is misjudged by the overall population. Social shame and preference added to the guardian distress.

Pattison et al. (1975) looked at social support by associating relational relationships of fearful and psychotic patients with those of normal individuals. They found that psychotic patients not only had the smallest number of persons in their social networks, but also that the network rarely extended beyond their family.

Turning to Religion is next major theme, noted from the participants' responses, regarding coping with their mentally ill relative, and was related to spirituality. The majority of the participants referred to the use of prayer and having faith in Allah as their most common coping strategy. Almost all of the participants referenced using some type of spirituality in their responses. Statement and responds from the participants are, female participant (F4) said that

“We are punctual in our prayers , recite holly Quran and we believe that mother’s pray accept by Allah soon or later it is by Allah no one other can do better for us. My sister is also punctual and offer prayers on time and recitation of Quran is in her routine”.

On the other hand, male participant (M1) said that

“We are poor people we belong to lower class. For a long time we spent a lot of money to get rid from ghost and bad evils. Taveed and religious tasbeeh (dam drood) you can say these peer type people take a lot of money but failed to treat her”.

People devote themselves to religious activities, as they think and have faith on this that if they will get more close to the religion they will get peace and feel comfortable. On the other hand peers and relative take the mental disorders as unspiritual powers have get over the person they force them to get some sort of “Tawiz” for the cure of the person. Some parents to the shrines for the treatment according to them they get better here rather than getting other treatments.

Next major theme extracted from the responses of participants is “Life situations”. Life of the family members who are living with the mentally disturb person become so tough, they cannot move in the society easily and cannot concentrate on their daily life. Society member don’t like to meet them warmly and avoid to make relation with them. If male member is going through mental disorder and he is the only money earning person in family then whole family goes through the financial issues. People start feeling hopeless and unlucky they don’t find way to get out of this situation. Some relatives with metal disorder use avoidant methodologies to cope to their circumstance. Escaping is a feeling centered adapting practice that a few families use when they overestimate the risk of the sickness or think little of their own managing ability

Female participant (F4) responded regarding the life circumstance *“It is too difficult to face society because you know in our society physical illness is acceptable but mental illness looks like a bad luck, or you can say accept negatively.”*

Other female participant (F3) said that *“Failure, hopelessness and helplessness are my life achievements. I think I should also commit suicide hopefully I will get rid from every tension and problems. People hate us avoid us don’t want to keep relation with our family”*.

On financial issue one of the female participant (F3) said *“I am not financially strong my father and elder brother are helping me but how long they will help us”*.

Ansa Talib: A Qualitative Approach to Study Differences in Well-Being and Experiences of Male & Female Caregivers Living with Mentally Disturbed Patients

Male participant (M1) respondent that *“Sometime I feel that I am not only unlucky but also helpless person. I am feeling hopelessness and tense about how my daughters will survive with these type of negative things”*.

Finding of the other research by Song et al. (1997) reported that higher levels of patient’s behavioral issues are linked with higher levels of caregiver depressive symptomatology among lower social class caregivers of persons with severe mental illness.

Gender disparities is the second last theme of extracted from the responses of the participants. Gender disparities are associated with the unequal behavior or treatment with one on the base of gender. It includes different initial themes like societal pressure on female, stereotypes about females and violence on the females’ etc. if any of the family member is having any sort of mental disorder that mostly effects the life of a female.

On this female participant (F3) said that *“No one like to send proposal for our younger sister due to the illness of my brother, if brother is suffering from mental disorder his sister will also have some problems like this”*.

One of the male participant (M2) said that *“We have to hide the disease of our son because my daughter is still unmarried so it will become hurdle for finding her good mate for marriage”*.

Last theme of our study is about the coping tacit and it includes constructing positive thinking, motivation and removing stress etc. Care givers communicated an extensive variety of feelings in their caregiving part going from concern, panic, disappointment, anxiety, bitterness, pain, displeasure, hatred, and blame to trust, mindful, empathy, sensitivity and adoration. The feelings changed every now and then, while looking after their relative. Both positive and negative feelings were reflected at various times.

Female participant (F5) said that *“We are trying to reconstruct positive thinking and remove stress from our lives”*. Care givers plays a fundamental part in supporting relatives who

are weak or disabled. There is most likely the groups of those with mental issue are influenced by the state of their close ones. Families give viable help and individual consideration as well as give enthusiastic backing to their relative with a mental issue. Consequently the influenced individual is issue to the caregiver, and their prosperity is straightforwardly identified with the nature and nature of the consideration gave by the care giver.

Results of the present study are supported by the Doornbos (1997), who studied the problems and coping methods of caregivers of young adults with mental illness, found that caregivers struggled with burden, grief, client symptomatology, and a negative impact on their family as a unit. The coping methods included facilitative attitudes, reliance on their faith, use of support groups, and increasing their knowledge of mental illness. Another literature of Crotty and Kulys (1986) support the result of the present study as he said that the patient's support system was an important mediator of family burden. Patients with a support system were less of a burden to their families than patients without a support system.

Implication

Current study has focused on a very important and sensitive issue. Providing care for people especially relatives with MI is difficult. And when it comes to someone closely related to us it is very painful experience. Our findings have shed light on how care providers living with MI patients face problems in different aspects of life health practices, accountabilities and duties, turning to religion, social stigma, life situations, and gender disparities. Since most of the researcher focus on the experiences and behaviors of psychiatric patients but there is no significance work done on the experiences of their family members which are greatly disturbed by their illness. Current study have shed light on how psychologists can assess and guide the behavior of caregivers of psychiatric patients, as reported by researchers from India that participation of

Ansa Talib: A Qualitative Approach to Study Differences in Well-Being and Experiences of Male & Female Caregivers Living with Mentally Disturbed Patients

families did lead to better outcomes in patient conditions, also the importance of providing them support and education did lessen the burden and stress faced by the families (Ballal et al., 2019).

Limitations

Interviews were only conducted in urban hospitals. Interviews were conducted in hospital settings, so there was no control over extraneous variable. Focus groups can be conducted for the further researches on the same topics for more information. Current study included only few family care providers for psychological disorders, future studies should cover other types of psychological patients so that the findings could be more generalized. Present research was conducted by the family care giver further can be on the nurse caregiver in the hospital settings.

Future Recommendations

Current research was qualitative based, future research can be done in quantitative perspective. For current research the sample size was small, future research can be done on large sample so that the results can be more generalized. Current research focused on family caregiver, future research can be conducted on nurses in hospital setting who tend to MI pateints.

Conclusion

Results of the study indicated that having any of the family member with a psychological disorder can be very distressing. Whether the individual, spouse, child or sibling you will be influenced by their mental disorder issues as well. A psychiatric issue person frequently needs much love, comfort and assistance. In the meantime, the issues, fears and manner of your sick relative may strain your understanding and your capacity to adjust. There are a wide range of sorts of emotional instability, and each has its own particular side effects. When your relative is sick, he/she might feel difficult, or awfully drawn back and inert. Truth be told, an individual's behavior may continue changing on the grounds that the side effects may vary. Social supports matter with coping mental disorder but in our society people cut off with the families whose member are having

any sort of mental disorder, although they need a lot of support, love and care from them which can help them in coping with the difficult situation. On the other hand results indicated that life of the females are more affected if any of the member is suffering from any sort of the mental disorder , they become victims of the violence and face problems in their marriages on the other side male face problem in moving society and having less jobs facilities etc. In the end results also indicated that family is disturb if any member is facing mental disorder.

References

- Ae-Ngibise K. A., Doku, V. C. K., Asante, K. P., Owusu-Agyei, S. (2015). The experience of caregivers of people living with serious mental disorders: a study from rural Ghana. *Global Health Action*, 8, 257- 269.
- Andren, S., & Elmståhl, S. (2008). The relationship between caregiver burden, caregivers' perceived health and their sense of coherence in caring for elders with dementia. *Journal of clinical nursing*, 17(6), 790-799.
- Angermeyer, M. C., Kilian, R., Wilms, H-U, & Wittmund, B. (2006). Quality of life of spouses of mentally ill people. *International Journal of Social Psychiatry*, 52, 278–85.
- Ballal, D., & Navaneetham, J. (2018). Talking to children about parental mental illness: The experiences of well parents. *International Journal of Social Psychiatry*, 64, 367–73.
- Berkshire, S. D. (2007). The Practice of Human Resources Management in the 21st-Century Healthcare Organization. *Managing Human Resources in Health Care Organizations*, 31.
- Biegel, D. E., Milligan, S., Putnam, P., & Song, L. (1994). Predictors of burden among lower socioeconomic status caregivers of persons with chronic mental illness. *Community Mental Health Journal*, 30(5), 473-494.
- Calasanti, T., & Bowen, M. E. (2006). Spousal caregiving and crossing gender boundaries: Maintaining gender identities. *Journal of Aging Studies*, 20, 253–263.
doi:10.1016/j.jaging.2005.08.001
- Calhoun, P. S., Beckham, J. C., & Bosworth, H. B. (2002). Caregiver burden and psychological distress in partners of veterans with chronic posttraumatic stress disorder. *Journal of traumatic stress*, 15(3), 205-212.
- Caregiver. (2015). *APA dictionary of psychology*. Washington, DC: American Psychological Association.
- Caqueo-Urizar, A., Maldonado, J. G., & Miranda-Castillo, C. (2009). Quality of life in caregivers of patients with schizophrenia: A literature review. *Health and Quality of Life Outcomes*, 7, 84.
- Carroll, M., & Campbell, L. (2008). Who now reads Parsons and Bales? Casting a critical eye on the “gendered styles of caregiver” literature. *Journal of Aging Studies*, 22, 24–31.

- Chadda, R. K. (2014). Caring for the family caregivers of persons with mental illness. *Indian Journal Psychiatry*, 56(3), 221–227.
- Chappell, N. L., Dujela, C., & Smith, A. (2014). Spouse/child differences in caregiving burden. *Canadian Journal on Aging*, 33, 462–472.
- Cheng, S., Lam, L. C., & Kwok, T. (2013). Neuropsychiatric symptom clusters of Alzheimer disease in Hong Kong Chinese: Correlates with caregiver burden and depression. *American Journal of Geriatric Psychiatry*, 21, 1029–1037. doi:10.1016/j.jagp.2013.01.041
- Cook, J. A. (1988). Who "mothers" the chronically mentally ill? *Family Relations*, 42-49.
- Crotty, P., & Kulys, R. (1986). Are schizophrenics a burden to their families? Significant others' views. *Health & Social Work*, 11(3), 173-188.
- Dixon, L., McFarlane, W. R., Lefley, H., Lucksted, A., Cohen, M., Faloon, I., Mueser, K., Milkowitz, D., Solomon, P., Sondheim, D. (2001). Evidence-based practices for services to families of people with psychiatric disabilities. *Psychiatric Services*, 59, 903–910.
- Doornbos, M. M. (1997). The problems and coping methods of caregivers of young adults with mental illness. *Journal of Psychosocial Nursing and Mental Health Services*, 35(9), 22-26.
- Durayappah, A. (2011). The 3P Model: A general theory of subject well-being. *Journal of Happiness Studies*, 12(4), 681-716.
- Flisher, A. J., Lund, C., Funk, M., Banda, M., Bhana, A., Doku, V., Drew, N., Kigozi, F. N., Knapp, M., Omar, M., Petersen, I., & Green, A. (2007). Mental health policy development and implementation in four African countries. *Journal of health psychology*, 12(3), 505–516. <https://doi.org/10.1177/1359105307076237>
- Gallagher, A. M., Setakis, E., Plum, J. M., Clemens, A., & van Staa, T. P. (2011). Risks of stroke and mortality associated with suboptimal anticoagulation in atrial fibrillation patients. *Thrombosis and Hemostasis*, 106(5), 968-977.
- Garlo, K., O'Leary, J. R., Van Ness, P. H., & Fried, T. R. (2010). Burden in caregivers of older adults with advanced illness. *Journal of the American Geriatrics Society*, 58, 2315–2322. doi:10.1111/j.1532-5415.2010.03177.x
- George, L. K. (1994). Caregiver burden and well-being: An elusive distinction. *Gerontologist*, 34, 6-6.
- Goldsworthy, B., & Knowles, S. (2008). Caregiving for Parkinson's disease patients: An exploration of a stress-appraisal model for quality of life and burden. *Journals of Gerontology, Series B*, 63, 372–376.

Ansa Talib: A Qualitative Approach to Study Differences in Well-Being and Experiences of Male & Female Caregivers Living with Mentally Disturbed Patients

- Hasui, C., Sakamoto, S., Sugiura, T., Miyata, R., Fujii, Y., Koshiishi, F., & Kitamura, T. (2002). Burden on Family Members of the Mentally Ill: A Naturalistic Study in Japan. *Comprehensive Psychiatry*, *43*(3), 219-222
- Horwitz, A. V., & Reinhard, S. C. (1995). Ethnic differences in caregiving duties and burdens among parents and siblings of persons with severe mental illnesses. *Journal of Health and Social Behavior*, *36*(2), 138-150.
- Jungbauer, J., Wittmund, B., Dietrich, S., Angermeyer, M. C. (2004). The disregarded caregivers: subjective burden in spouses of schizophrenia patients. *Schizophrenia Bulletin*, *30*, 665-675.
- Kim, H., Chang, M., Rose, K., & Kim, S. (2012). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing*, *68*, 846–855. doi:10.1111/j.1365-2648.2011.05787.x
- Kim, Y., Baker, F., & Spillers, R. L. (2007). Cancer caregivers' quality of life: Effects of gender, relationship, and appraisal. *Journal of Pain and Symptom Management*, *34*, 294–304. doi:10.1016/j.jpainsymman.2006.11.012
- Larson, J. E., & Corrigan, P. (2008). The Stigma of Families with Mental Illness. *Academic Psychiatry*, *32*, 87–91.
- Leroi, I., Harbissettar, V., Andrews, M., McDonald, K., Byrne, E. J., & Burns, A. (2012). Carer burden in apathy and impulse control disorders in Parkinson's disease. *International Journal of Geriatric Psychiatry*, *27*, 160–166. doi:10.1002/gps.2704
- Lethin, C., Renom-Guiteras, A., Zwakhalen, S., Soto-Martin, M., Saks, K., Zabalegui, A., Challis, D.J., Nilsson, C., & Karlsson, S. (2017). Psychological well-being over time among informal caregivers caring for persons with dementia living at home, *Aging & Mental Health*, *21*(11), 1138-1146, DOI: 10.1080/13607863.2016.1211621
- Mattejat, F., & Remschmidt, H. The children of mentally ill parents. *Deutsches Ärzteblatt International*, *105*(23), 413-418
- McDonnell, M. G., Short, R. A., Berry, C. M., & Dyck, D. G. (2003). Burden in schizophrenia caregivers: Impact of family psychoeducation and awareness of patient suicidality. *Family process*, *42*(1), 91-103.

- Mohamed, S., Rosenbeck, R., Lyketsos, C. G., & Schneider, L. S. (2010). Caregiver burden in Alzheimer disease: Cross-sectional and longitudinal patient correlates. *American Journal of Geriatric Psychiatry*, 18, 917–927. doi:10.1097/JGP.0b013e3181d5745d
- Navaie-Waliser, M., Feldman, P. H., Gould, D. A., Levine, C., Kuerbis, A. N., & Donelan, K. (2002). When the caregiver needs care: The plight of vulnerable caregivers. *American Journal of Public Health*, 92, 409–413. doi:10.2105/AJPH.92.3.409
- Ogilvie, A. D., Morant, N., & Goodwin, G. M. The burden on informal caregivers of people with bipolar disorder. *Bipolar Disorder* 2005, 7(1), 25-32.
- Pattison, E. M., DeFrancisco, D., Wood, P., Frazier, H., & Crowder, J. (1975). A psychosocial kinship model for family therapy. *The American Journal of Psychiatry*, 132(12), 1246–1251. <https://doi.org/10.1176/ajp.132.12.1246>
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist*, 30, 583–594. doi:10.1093/geront/30.5.583
- Pompili, M., Harnic, D., Gonda, X., Forte, A., Dominici, G., Innamorati, M., Fountoulakis, K., Seraini, N., Sher, L., Janiri, L., Rihmer, Z., Amore, M., & Giradi, P. (2014). Impact of living with bipolar patients: Making sense of caregivers' burden. *World Journal of Psychiatry*, 4(1), 1-12.
- Robinson, J., Fortinsky, R., Kleppinger, A., Shugrue, N., & Porter, M. (2009). A broader view of family caregiving: Effects of caregiving and caregiver conditions on depressive symptoms, health, work and social isolation. *Journals of Gerontology Series B: Psychological Sciences*, 64B, 788–798.
- Rolland, J. S. (1994). *Families, illness, and disability: An integrative treatment model*. New York: Basic Books.
- Rosdinom, R., Zarina, M. Z., Marhani, M., & Suzaily, W. (2013). Behavioral and psychological symptoms of dementia, cognitive impairment and caregiver burden in patients with dementia. *Preventive Medicine*, 57, S67–S69. doi:10.1016/j.ypmed. 2012.12.025
- Ryan, C., Russell S. T., Huebner, D., Diaz, R., & Sanchez, J. (2010). Family acceptance in adolescence and the health of LGBT young adults. *Journal of Child and Adolescent Psychiatric Nursing*, 23(4), 205-213.
- Saunders, J. C. (2003). Families living with severe mental illness: a literature review. *Issues in Mental Health Nursing*, 24, 175–198.

Ansa Talib: A Qualitative Approach to Study Differences in Well-Being and Experiences of Male & Female Caregivers Living with Mentally Disturbed Patients

- Siddiqui, S., & Khalid, J.(2019). Determining the caregivers' burden in caregivers of patients with mental illness. *Pakistan Journal of Medical Sciences*, 35(5):1329-1333. doi: <https://doi.org/10.12669/pjms.35.5.720>
- Shakeel, S., Rana, S. S., & Malik, N. I. (2015). Burden of care, mental health and subjective wellbeing of family caregivers of elderly patients. *Pakistan Journal of Professional Psychologists*, 6(1), 1-15.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. Los Angeles, CA: SAGE
- Song, L. Y., Biegel, D. E., & Milligan, S. E. (1997). Predictors of depressive symptomatology among lower social class caregivers of persons with chronic mental illness. *Community mental health journal*, 33(4), 269-286.
- Ssebunnya, J., Kigozi, F., Lund, C., Kizza, D., & Okello, E. (2009). BMC International Health and Stakeholder perceptions of mental health stigma and poverty in. *BMC International Health Human Rights*, 9, 1–9.
- Tull, M.T., Barrett, H.M., McMillan, E.S., & Roemer, L. (2007). A preliminary investigation of the relationship between emotion regulation difficulties and posttraumatic stress symptoms. *Behavior Therapy*, 38(3), 303-313.
- Yamazaki, S., Sokejima, S., Mizoue, T., Eboshida, A., & Fukuhara, S. (2005). Health-related quality of life of mothers of children with leukemia in Japan. *Quality of Life Research*, 14(4), 1079-1085.
- Zarit, S. H., Kim, K., Fernia, E. E., Almeida, D. M., Savla, J., & Molenaar, P. C. M. (2011). Effects of adult day care on daily stress of caregivers: A within person approach. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 66B, 538– 546. doi:10.1093/geronb/gbr030