

Experiences Of Informal Caregivers Of Persons With Parkinson's Disease (PD) In Punjab, Pakistan: A Qualitative Approach

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Abstract

Background: Patients has lost control over limbs which resulted in losing mobility to do actions as result to which they are completely dependent on their caretakers. Such condition of dependency has made caretakers socially inactive, fatigued and incapacitated. Their suffering is equal to the patient. As every caretaker narrates that feel him/herself as a patient. People with Parkinson's disease need a full time caregiver to provide care on daily basis. The purpose of this study is to explore the impact of Parkinson's disease on patients and their caregivers regarding their socio-economic aspects along with physical and psychological issues.

Materials and Methods: Qualitative data was obtained through survey from ten (N=10) caretakers of Parkinson's disease patients through In-depth interviews using purposive sampling with help of Interview guide containing research related questions. Thematic analysis was applied to analyze the data.

Results: Findings showed that caregivers of Parkinson's disease clearly affecting from continuous stress and tough routine while serving their patient. Sufferings of caregivers are multiple in nature which are tempering them socially, psychologically and also economically as well.

Conclusion: Parkinson disease has paralyzed not only the patients but also their caretakers. As a result there is not only one patient but Parkinson has paralyzed two individuals from each family and one associated member who further takes care of the caretaker. Such condition of dependency has made caretakers socially inactive, fatigued and paralyzed. Their suffering is equal to the patient.

Keywords: Parkinson's Disease, Informal Caregivers, Activities of Daily Life, Neurological Disturbances

Introduction:

Parkinson's disease is a complex neurodegenerative progressive disease process having multiple clinical, social, psychological and physical manifestations. The person with Parkinson disease have number of problems such as mobility restrictions, vivid dreaming, hallucination that can affect sleep quality; confusion, depression that affect psychological well-being (Carter et al., 2008). These symptoms pose the restrictions on the patients to take part in daily life activities significantly and incorporate in social and recreational activities. Such pattern of life mainly affects the quality of life (Pretzer-Aboff, 2009).

From the beginning, people with Parkinson's require attention in a several way. Many services are required to the patients such 2011as occupational, physical and recreational; often these services are provided by the family members and friends at home. Informal caregivers play vital role because they involve individual in daily life activities resulted in people with Parkinson's feel better to perform. It is admitted fact that care giving process has adverse effects on the health of informal family care-givers (Northwest Parkinson's wellness centre, 2011).

It is estimated that one in six individuals are stricken with some kind of neurological disturbances worldwide. It is the fact that 7-10 million people suffer from the Parkinson's disease throughout the world. 1-3 million people are plagued with Parkinson's disease in the United States of America (USA) (Parkinson's disease Foundation). The facts reveal that most of the Parkinson's patients cured in the age of the sixties; though, it can affect individuals as early as in the third or fourth decade of life. The risk and prevalence of this neurological disorder is

growing with age (United Nations, UN News Centre; 2007). People with Parkinson's disease need a full time care-giver to provide care on the daily basis. United States economy bears \$25 billion per year costs on Parkinson's disease in the terms of Social Security payments, medical treatments and lost income. Despite all this, it is considered that Healthcare professionals ignore the burden of care-givers; they all focus on the care and cure on Parkinson's patients. Therefore, it is highly concern that Healthcare professionals assess the needs and burdens of the informal care-giver, including how the care they provide relates to healthcare costs (Kelly et al., 2012).

Parkinson's disease poses several restrictions on the physical, social, psychological and financial domain of the informal care-givers. Informal care-giver spends more time with patient to engage him in daily life activities. For the care-givers, adaptation to new settings of life causes the isolation. Furthermore, care-givers of people with Parkinson's disease also suffer anxiety, depression and sleep disturbances. It is stated that financial stability is essential for providing care to people with Parkinson's disease because isolation, emotional and financial barriers are the outcome for many informal care-givers (De Villiers et al., 2008).

Objective of the Study

To explore the socio-economic impact of Parkinson's disease on patients and their caregivers.

Literature Review:

Vitaliano and Katon (2006) examined that Parkinson's disease is a physical and mental disabling. It is not only for the people with Parkinson's disease but also for the informal care-givers. Despite this, informal caregivers bear the financial constraints directly and

indirectly. Both researchers have highlighted the relationship between burden and well-being of care-givers of people with Parkinson's disease. They found that caregiver stressors harmfully linked to care-giver burden and in turn care recipient quality of life. Second, they found the frequency of breaks and perceived social support to improve the effects of caring on burden and in turn quality of life. Finally, they found the caregiver care recipient relationship to enhance the effects of caring on burden and quality of life.

Tan et al. (2012) conducted a study using an in-depth interview to analyze the experiences of people of Singapore affected by Parkinson's disease (PD). They founded that it is primarily to provide care to people with Parkinson's disease (PD) because caregiving process will ameliorate their quality of life and increase their life expectancy. Providing care in their homes also provides psychological support as well as reduces health care costs.

Bhimani (2014) conducted a study and defined that informal caregivers are counted key assets of healthcare system because they deliver their services to the people affected by Parkinson's disease. Researcher examined that clinicians only focus on the health and needs of patients; they ignore the health and needs of family caregivers. Researcher conducted this study "Understanding the burden on caregivers of people with Parkinson's: A scoping review of literature" with the purpose to detect the burdens on care-givers of people with Parkinson's disease. Researcher found that there is a sheer need to intervene workable activities that minimize physical, socio-economic and psychological barriers of caregivers.

Theed et al. (2016) conducted a research and recommended that it is important to highlight issues faced by informal care-givers of people

with Parkinson's disease. There is a need to identify aspects because most distress to informal caregivers. Researcher identified that movement problems and dependence in activities of daily life directly related to the caregivers' psychological concern. It is noted that people with Parkinson's disease have lower level of cognitive functions and higher level of depression that create psychosocial barriers for informal caregivers. Researcher suggested that workable psychosocial actions can prove helpful in minimizing distress of informal caregivers.

Hempel et al. (2008) examined thirty (30) researches to frame understanding regarding psychosocial interventions which can prove supportive for informal care-givers. After reviewing studies, researcher suggested that day care, night-sitting services, community care assessment. Besides, video based lectures, formal education classes, and support groups are also very important in improving the quality of life of informal care-givers. It is fact that most of the caregivers are female who have not sufficient knowledge and training that creates physical and psychosocial constraints for them. Researcher concluded that family and social support are compulsory to increase the functional capacity of informal caregivers of people with Parkinson's disease.

Methods and Materials:

For this study, total (N=10) In-depth interviews conducted from the caretakers of Parkinson's disease patients. Purposive sampling technique was used for selection of respondents by keeping in view the nature and demand of study. A semi-structured Interview schedule used to conduct interviews by using possible relevant questions for the purpose of addressing social, physical, psychological and economics aspects of the patient and his/her family.

Table 1. Demographic Characteristics of Respondents (N=10)

Demographic Variables	Total Sample (N=10)	Percentage (%)
Patients (Gender)		
Male	6	60%
Female	4	40%
Informal Caregivers (Gender)		
Male	6	60%
Female	4	40%
Patients Age		
<20	-	-
21-30	-	-
31-40	-	-
41-50	3	30%
>50	7	70%
Informal Caregivers Age		
<20	-	-
21-30	4	40%
31-40	6	60%
41-50	-	-
>50	-	-
Patients Educational Status		
Illiterate	3	30%
Primary School	2	20%
Secondary School	2	20%
Intermediate	-	-
Graduation	3	30%
Master	-	-
Above	-	-
Informal Caregivers Educational Status		
Illiterate	3	30%
Primary School	1	10%
Secondary School	1	10%
Intermediate	2	20%
Graduation	1	10%
Master	1	10%
Above	1	10%
Relation of Informal Caregivers with patients		
Son	6	60%
Daughter	3	30%
Brother	-	-
Daughter In law	1	10%

Others	-	-
Patients Occupation		
Farmer	4	40%
Housewife	3	30%
Employee	3	30%
Businessmen	-	-
Others	-	-
Informal Caregivers Occupation		
Farmer		
Housewife	5	50%
Employee	2	20%
Businessmen	1	10%
Students	-	-
Others	2	20%
-	-	-
Residential Area		
Rural	6	60%
Urban	4	40%

1	Q. 1. History of Patient?
2	Q. 2. How do you help him in managing his ADLs?
3	Q. 3. What are the economic cost of the disease and impacts on the family?
4	Q. 4. What are the psychological impacts on you as a caregiver in managing this disease?
5	Q. 5. How do you maintain your health to care for the patient of Parkinson & to take care of yourself?
6	Q. 6. What are social implications for you as a primary caregiver?
7	Q. 7. What is the response of other family members towards you and patient?
8	Q. 8. Does the patient participate in different Recreational/Leisure activities?

Table 2. Interview Guide for In-depth Interview**Thematic Analysis:****Theme I: History, symptoms and effects of Parkinson's disease (PD)**

Data elements related to this theme were identified by questioning the informal caregivers about history, symptoms and effects of Parkinson's disease on patients. The data revealed that all the patients (men & women) with Parkinson's disease (PD) were socially active and performed their daily life activities vigorously before suffering this disease. At initial stage, the informal caregivers noted symptoms as headache, fragile and weak hand-grip, weakness, anger,

depression, isolation, swing mood and unable to perform activities of activities of daily life. According to informal caregivers, Parkinson's Disease (PD) had severe effects on their social, psychological and physical health. The persons with Parkinson's disease (PD) had physical restrictions, lingering speech power, anxiety, depression, dependency, social isolation, forgetfulness and uncertain behavioral changes.

Theme II: Role of Informal Caregivers in managing ADLs of person with Parkinson's disease (PD)

Across the In-depth interviews, the vast majority of informal caregivers responded that they had deleterious situation in managing activities of daily life of person with Parkinson's Disease (PD). They cannot maintain balance between their own necessities and daily life activities of person with Parkinson's Disease (PD). In our transcript, informal caregivers demonstrated their roles in terms of changing dress, to provide help in taking bath and medicines. One of the informal caregivers said,

"I assist in Wazu when my father is in toilet".

Another informal caregiver said that,

"I help my father in writing articles, speaking, dialing numbers and writing messages".

Social supportive environment and emotional affiliation emerged as another related theme. Most of the informal caregivers demonstrated that social supportive environment and emotional affiliation is essential to maintain the physical and psychological health of person with Parkinson's Disease (PD).

Theme III: Social Implications of Parkinson's disease (PD) on informal caregivers

To know the social implications of Parkinson's Disease (PD) on informal caregivers, informal caregivers were asked tell about the social implications of Parkinson's Disease (PD), what they had realized in providing care to the person with Parkinson's Disease (PD). One thing is found common in all respondents that they had active participation in their social life and free from any social limitations before providing care to the person Parkinson's Disease (PD). Informal caregivers demonstrated that providing care to the person with Parkinson's Disease (PD) had great effects on their social life and marital life. One of the female informal caregiver said that:

It has been three year since I took admission in M.Phil. Only coursework has yet been

completed. All of my time utilize in proving care to my mother.

Another respondent commented that:

"I have two children. If I look upon my social life, so it's also my responsibility to give proper time to my children and their needs come first but I couldn't give them proper time. My life is being finished while taking care of my father".

One of the young female informal caregivers demonstrated that:

It seems dream to think about my own self. I no more like the girl. The girls of my age are different and their dreams are vibrant but I can't think of that. I have sacrificed myself for the sake of my home. Mother's disease has a disastrous impact on my life and my life is over.

All the informal caregivers said that they cut off from their social life and they are just limited to person with Parkinson's Disease (PD). Parkinson's Disease (PD) has posed social limitation in different form in their lives.

Theme IV: Financial implications of Parkinson's disease for informal caregivers

Data relevant to financial implications of Parkinson's Disease (PD) is reflect that it is depend on the financial background of the person with Parkinson's Disease (PD), otherwise the treatment of this disease is not expensive. One can manage in easy way. On the other hand, Parkinson's Disease (PD) pose great financial implications for the informal caregivers.

One of the informal caregivers demonstrated that: "Financially I depend on the other members of the family because to provide care to person with Parkinson's Disease (PD) is a twenty four hours job".

Most of the informal caregivers said that they have no any financial activity to earn; they are

just limited to the caregiving. This thing leads to the psychological disturbances.

Theme V: Psychological impacts of Parkinson's disease (PD) on informal caregivers

Psychological impacts of Parkinson's Disease (PD) on informal caregivers were significant. Relevant data depicted that due to heavy load of caring on informal caregivers suffer then in mental stress, depression, anxiety, hypertension, physical weakness and insomnia. One of the young girl informal caregiver stated that:

“..... All of my time utilize in caring resulted in I could not complete my education. All these things are causing mental damage. I remain in stress, physical weakness”.

Another informal caregiver demonstrated that: “Human can take care of others when he is healthy. When father became ill, I was healthy both mentally and physically. I had courage and strength. But with the passage of time, I started neglecting myself and nutrition. It is a fact that a caretaker cannot take care of himself. He gives importance to patient's health. My health has been ruined and weakness, tempered, annoyed, depression all these things are now part of my life”.

One of the female informal caregiver said that: “I cannot manage my house in this condition then how I can take care of myself? I take sleeping pills at night. Weakness, headache, getting faint is normal routine. There is so much pressure on me of house and mother's condition. I cannot get time for me”.

One of the responded demonstrated that: “Supportive family environment assist you psychologically. I provide care to my father and others members of family provide care to me and give proper time to facilitate me in every affairs of my life”

Theme VI: Suggestions to maintain health of persons with Parkinson's disease and informal caregivers

Data relevant to this theme is depicted that health is real blessing. Healthy body and healthy mind are interconnected. One thing is common in all informal caregivers is that positive family behavior's and pleasant domestic environment are essential for the health of person with Parkinson's Disease and informal caregivers. One of the informal caregivers said that:

“We can easily deal with the patient of Parkinson's if we get proper family support and healthy social environment”.

Participation of person with Parkinson's Disease (PD) in social and recreational events are essential for their normal health. These things give them meanings of life. Person with Parkinson's Disease (PD) likes family, social and medical support. They feel fresh after having get together with fellows and friends.

Another informal caregiver demonstrated that:

“If caretaker is healthy, he can better take care of the patient. My family members take care of myself and support me in every aspect of life”.

Most of the informal caregivers claimed that sharing responsibilities regarding provision of care to person with Parkinson's Disease (PD) is important factor in maintaining health of informal caregiver.

Across all the in-depth interviews, most important thing is that wife has important role in providing care to her husband if her husband is informal caregivers of person with Parkinson's Disease (PD). One of the informal caregiver comment that:

“My wife helps me and scolds me that I do not take care of my health. I think it is due to my wife

who really cares about my health and that's why I am able to take all these responsibilities".

Most of the informal caregivers demonstrated that emotional and psychological support, pleasant domestic environment and counseling of patient pave the ways in which informal caregivers provide the care to person with Parkinson's Disease properly.

Conclusion:

Parkinson's disease is a disabling disorder of movement. It affects the way a person moves. It happens when there is a problem with certain nerve cells in the brain. These nerve cells make an important chemical called dopamine. This chemical send signals to the part of a brain that controls movement. It is still unclear how dopaminergic denervation perverts normal functioning to cause slowing of voluntary movements. This disease according to caretakers of Parkinson 'patient can cause psychological disorders, physical weakness, dependency, apathy, socially inactive and erectile dysfunction. The most dreadful thing is that it doesn't only effect the patient but directly effects caretaker and other family members.

When a person becomes victim, he starts complaining undue stress or weakness, without realizing that he has someone serious to get medical care. With the passage of time patient begins to face Akinesia where he finds difficulty in producing movements as caretakers narrate that the patient was healthy and socially active. With the passage of time he begun to have anger, anxiousness and other psychological issues which ultimately resulted in Akinesia where they found patient dropped into the bathroom or patient him/herself become isolated. Parkinson disease has paralyzed not only the patients but also their caretakers. When caretakers are asked about psychological issues they face while caretaking. They all have same issues as the patient him/herself is suffering from. The social

life circle of both, the patient and the caretaker, has been detached from society as well as from their own families.

Before disease patients used to attend ceremonies, harvest their lands, use to walk on long distances and fulfilled their social hierachal roles. All patients belong to different fields e.g. lawyer, teacher, mother, father, husband, writer, former etc. thus the data can reflect the maximum field of life affected by Parkinson. All above professionals, most among them are sole earner and regulate household, became socially inactive, drenched into sorrow and paralyzed in every aspect of life. Moreover, due to the disease they face Ataxia which means they cannot maintain their balance which means they cannot holdup themselves together. Atheros's is another problem which persists in involuntary actions. Which can also found in the patients under observation. Patients has lost control over limbs which resulted in losing mobility to do voluntarily actions as result to which they are completely dependent on their caretakers. Such condition of dependency has made caretakers socially inactive, fatigued and paralyzed. Their suffering is equal to the patient. As every caretaker narrates that feel him/herself as a patient.

All their social activities have been omitted to such extent that their marital life seems suffocating. For male caretakers, it seems easy to help their patients but even male members of society cannot fight with such circumstances. Moreover they feel isolated even if they are married. Their family responsibilities seems to add into burden instead of giving them comfort. They are unable to give time to their children and wife, which results in domestic fights and sense of losing their blood relations. It indicate that the main key to society, parental responsibilities, cannot be fulfilled. Such disease are threat to form a healthy families. If men cannot deal with such environment than those females definitely

suffer more. Females are unable to even think of themselves. In most of cases, it can be observed that families in which the female caretakers are not married, their future seems in dark. They are already over aged and there is no further possibilities to get married or to even think of their personal life. Their family consider it as their obligation to serve the patient. The patient is either mother or father and every patient was an essential member of the family who took care and facilitate their children. After becoming patient, now the eldest child or the one who was emotionally attached to his/her parents performs as their caretaker. Either they are male or female, married or unmarried, they all are suffering from same domestic issues as well as psychological disorders. They all have become physically weak and are unable to take care of themselves. They are as dependent on other family members like sister-in-law, sister, wife or other family members as patients depend upon them. As a result there is not only one patient but Parkinson has paralyzed two individuals from each family and one associated member who further takes care of the caretaker. Caretaker cannot survive without an additional supportive hand. Caretaker him/herself suffers from tension, depression, weak digestion, chronic pain, muscles restraint pain, unusual fever, high blood pressure, anxiety and more likely psychological and physical issues. Even after going through the hardest phrase of their lives, they tries to maintain healthy environment in order to keep patient as positive as possible. They took patient to the ceremonies, family functions, and cultural festivals whenever it seems possible for the patient to travel. Moreover it depends on his mode as patients also suffer from mode switch trauma but caretakers keep themselves calm and positive and becomes patients not only both hands but proficient narrators to express their emotions on gatherings as patients cannot speak fluently due to various linguistics disorders.

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