



An Exploratory Case Study to Understand Impact of Chronic Illness

¹Nishi Arora, ²Nidhi Shrivastav and ³Ravi Shrivastav

¹Associate Professor, Maulik Siddhant and Samhita Vibhag, A&U Tibbia College and Hospital, New Delhi

²Associate Professor and Head of Department, Anatomy, Government Ayurveda College, Jabalpur MP

³Associate Professor and Head of Department, Agad Tantra and Vyavhar Ayurveda Government Ayurveda College, Jabalpur MP

Received: 17-08-2017 / Revised Accepted: 27-09-2017 / Published: 29-09-2017

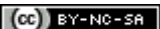
ABSTRACT

The paper is about a case study performed on a patient with chronic illness and his family. Two unstructured interviews were taken from the patient and his family members. One to one interview method was adopted to explore about the challenges, distresses and coping styles followed by the family. Analysis of the interviews was done to understand the in-depth feelings and struggles of the family. The major concerns for the patients were to deal with physical pains, emotional distress, frustration of decapacitation and limitations in personal and social life. Whereas the family was suffering from unending labor of caring for the patient and exhaustion of financial and social resources during the same exercise. It was concluded that this family was coping with the problems with a positive attitude where self-care was being attempted with the addition of seeking help from the social circle and the professional-like counsellor and physician. The patient was also prepared for his limitations and tried to divert himself with music and television while keeping himself busy with work.

Key words: Chronic illness, emotional distress, coping style, counselling.

Address for Correspondence: Dr. M.S. Shree Devi, Medical Officer, Siddha Central Research Institute, Arumbakkam, Chennai, India; E-mail: shreemd@gmail.com

How to Cite this Article: Nishi Arora, Nidhi Shrivastav, and Ravi Shrivastav. An Exploratory Case Study to Understand Impact of Chronic Illness. World J Pharm Sci 2017; 5(10): 34-36.

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INTRODUCTION

Ayurveda has become the choice of the masses in contemporary times. The reason being complexity of the diseases and lowering of the immunity in general. This mode of treatment has lot of potential to prevent and cure many of the diseases but its popularity in the society is its specialization to cure chronic diseases. That's the reason behind studying about a family which includes a chronic patient, system of the family and also to understand what kind of family support reaches out to the patient.

Objectives: The aims and objectives of the case study are:

1. To find out about the stressors of the patient suffering from chronic illness and also faced by the family of the patient.
2. To know about emotional and social impacts of chronic illness upon the patient and his family.
3. To know about the social support

MATERIAL AND METHODS

Material required-

- a. To interview schedules; one for the patient and one for the family members involved in case giving.
- b. Papers and pen were used to have one to one interview conduction.

Methods: The case was identified from the closed affinity i.e. from the society around. The patient was 48 years old. He was living with his mother, wife and daughter. He was suffering from Polymyositis. The illness started in 1999. The researchers approached him and explained him the purpose of the inquiry and a written consent from the patient was taken. The researchers also conducted his wife who was working with an embassy. She also gave her consent for the interview. The researchers reached at the appointment place and conducted the interview of respected days.

An unstructured interview that consisted of 31 questions was conducted with the patient and other unstructured interview containing 35 questions were asked from his wife.

Analysis and Discussion:

Analysis of the interview taken with the patient: The patient was suffering from his illness for last 14 years. He told that he also was gradual and the course of illness was progressive. The disease started with weakness in lower limbs. The critical phase lasted for 6 months. The patient faced a tough time initially. The physician could not diagnose anything and he became the victim of misdiagnosis. The things were deteriorating slowly,

and he had to use walkers sometime. He was treated even for tuberculosis of pelvic bone which was unfortunately not the case. In-fact it was polymyositis. When the diagnosis was established, the first reaction of the patient was a shock. He could not believe that it could never be cured. Only after 2-3 years he could realize that he had to accept its permanence. He got to know that is an Auto-immune disease with no cure available. He was broken down (emotional distress) from inside but outwardly showed his calmness because he knew that his parents would get into further distress if they see, their only son in a shattered state of mind. There was no family history of such disease. He was an intelligent patient so he tried to find out the scientific reasons behind the illness but couldn't get satisfactory answers. He turned back to traditional answers "Theory of Karma" and fate or destiny. He used to be an atheist before that. Changing belief system could be seen due to illness. The patient was apprehensive of his future health. It was a major cause of his worry. He needed assistance in his daily life like changing, bathing, grooming etc.

He felt embarrassments for the same. Feelings of Decapacitation also increased his distress and shame. His faith upon medical facilities was shaken. Financial crunch was an important issue in his opinion but he felt that he was lucky that his wife was earning well and the needs of the family were getting fulfilled. He still held his position in the family. His wife and mother were both caring and positive so they never let him realize that he was decapacitated. His daughter was loving. He was working for his friend as a planner to keep himself busy. He used to go with his family to frequent tours but now he could not do that. He was strong enough to overcome his frustration. He switched on his television to watch discovery channel. He imagined himself going to the places showed on this channel. His sexual life was affected badly because his lower limbs were so much atrophic and tender. In the times of extreme-distress he listened to ghazals and cried with those emotions and did not try to stop his tears.

Analysis of the Interview with the Family Members:

His wife felt depression and insecurity over his husband's condition. She was afraid that whether she would be able to handle the conditions or not if things deteriorate further. She was worried about her mother-in-law's health status because she was still sharing many responsibilities at home despite of her old age. Her wife meditated to relieve self from overburden of physical and mental exhaustion. She did not share her feeling with people outside the family in an apprehension that other people would try to take undue advantage of her vulnerable state. Inside the family Pink

Elephant in the room phenomenon was prevailed. Everybody knew that there was a problem but nobody wanted to talk about it. She took help from her counsellor who was with her for the last three years. Her health was also effected badly due to continuous stress and high levels of alertness. She was suffering from cervical spondylitis, diabetes and hypertension for last 4 years. Her food habits were effected. She had to cook two types of food in the family but received lesser time to relax and eat compared to before the patient got sick. Her sleep also got disturbed. Her social circle was contracting because of the compulsions that one member must always be at home for the patient. They couldn't plan holidays as the types of schedules or lifestyle needed for the patient was not possible to follow outside the home. Her household work was also affected because most of the time was being spent with the patient.

Other things at home were neglected. Obsession for cleanliness was increased to save the patient from secondary infections. Security of the house was another issue. The patient could not move on his own, mother in law was old and their daughter was young. When she used to leave home for office or else, she remained in a state of worry. Financial problem was there because expenditure of medicines, hospitalization and special requirements was really high. She had to compromise for her personal hobbies and likings. She couldn't spend leisure time for herself. The patient's daughter told that her father himself answered her queries about the illness. She also told that her father clearly explained about the challenges ahead for her and the family. It hurt her but she had no option but to bear. The patient's mother assumed that it's some kind of *Nazar Lagna* (impact of bad intensions of the people around). She tried her level best to overcome it by meeting with many *Pandits* and *Molvies* but anything could not work. She broke down to tears while accepting the disease of her only son by saying *jo Bhagwan ki marzi*.

CONCLUSION

It was concluded from the analysis of the interview with the patient with a chronic illness that it is very difficult for the patient to go through the critical phase. If the disease is progressive in nature, the

patient and his/her family gets time to accept and adjust according to the type of lifestyle required to handle the disease. The major concerns of the patient are emotional distress due to feeling of helplessness, frustration and varied pains. Changes in the belief system of the patient, financial worries, apprehensions about the future course of the disease, reduced self-esteem and endurance, marked limitation in socialization and support system. The other issues which are important concerns for the patients are the healthcare system, issue of willpower, compromising sexual life and attitude towards the illness. The family also suffers a lot. Certain key themes of the family's quality of life were identified for the interview these things included emotional impact, restricted daily activities, family relationships, sleep and health, holidays, involvement in medical care, social life and time management.

Reflections and Suggestions:

It was a very moving experience for the researcher to know about the hardships faced by the patient's family and the patient himself/herself. It was appreciable that every patient was trying hard to come out of the distress by using various means. In this case, the patient was using music or watching his favorite channel on tv to divert his attention. The patient's wife approached counsellor when she faced high emotional distress or used meditation practice to overcome the hardships. The patient's mother handled it with devotional practices towards her religion.

Suggestions:

Generally, patients with chronic diseases seek Ayurveda specialists since they are much needed to be counselled. The patient needs to develop acceptance and resilience towards the situations occurred due to illness in his personal and social life. The family should also be counselled to improve their coping mechanism i.e. to shift the coping from emotion focused style to problem-solving style. It can be suggested to relay information about the locations of rehabilitation centers and emergency services, and even about the policies introduced the government to help the families of the patients with chronic illness.

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