

A Case Study on Care Giving Among Mentally Disabled Persons in Institutionalized Settings

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Abstract: *Mentally retarded children are born to families in every strata of society, to the very poor and the very rich, the illiterate and the highly educated. Family members and care givers experience a wide range of powerful emotions in a response to a diagnosis of mental retardation, including denial, shock, anger, guilt, embarrassment, depression, withdrawal, ambivalence, disillusionment and fear. The influence of care givers among these people is important in day to day life, the personal and socio economic attitudes towards patients, and as discussed in this study. The study deals about the relationship between the care givers and the care recipient, the nature of the care recipient's disability and the stage of the care giving process.*

Keywords: Mental health, Disability, Mental retardation, Emotions, Care giver

1. Introduction

A care giver is defined as a relative, friend neighbor or a person who provides practical day- today unpaid or paid support for a person enable to complete all of the tasks of daily living. The care recipient is the person who lines some form of chronic condition that causes difficulties in completing the task of daily living.

Some people suffering from mental retardation are institutionalized while others live with their families. According to Burke and Cigno(1996:29) it seems probable that most caring is likely to take place within the immediate family household. With deinstitutionalization, more and more people are cared for in their homes. It is therefore important to realize that disabled people do not function in isolation.

The family had a vital role in an ill persons life in a community. They are first and best caregivers. But somehow here may be a barrier of physical and emotional distress by the family members than the paid or non professional caregivers. In an effort to provide the best possible care for a family member, care givers often scarifies their own physical and emotional needs for duty. Thus the presence and the care of caregivers, give a positive change in each persons who is ill. They expect more love and care from their caregivers, a silent smile and touch can make a better life in them. The importance of care givers in an institutional setting is differ from a family setting, the study make a comparison along paid and nonpaid care givers in an institutional setting.

2. Objectives

The major objectives of the study include,

- To understand the functioning of agency in terms of history, philosophy, vision, staffing, client population, organization structure, day to day functioning of the agency etc.
- To understand the role of care givers among mentally retarded persons.

- To analyses and understand institutional care and family care among respective fields.

3. Research Methodology`

The research methodology used for the study is case study method. The data collection tools that were employed in the research include structured questionnaire, interview guide, direct observation, and a pocket notebook. The data analysis was carried out during the research using qualitative methods. A qualitative method of analysis was also used to describe and interpret data mainly from the interview guide and data from secondary sources. The present study is held in the institutional setting of Sarvathrika Sahodarya Samithi (S.SSamithi) Kollam, is situated in the southwest corner of India in the state of Kerala.

4. Role of Care Givers

The mentally disabled persons needs more love and care but most of the time the society considers them as a burden for the community. The person who is mentally disabled act differently according to their behavioral change such that sometimes a 50 year old man may act as 5 year old boy. They may not be able to do any of their actual needs by themselves. In that condition there should be a person who needs to help the person that is the care giver. There are such institutions in Kerala which provide homely care for their patients, by promoting availability of Psychiatric social workers and care givers as paid agents. They do their work with professionalism. The impact of care giving among the inmates is important in an institution. The present study is held in the institutional setting of Sarvathrika Sahodarya Samithi (S.SSamithi). The presence of care givers helps the inmates to cope more with the society. Care givers play a major role in providing care giving assistance to ill persons and their families.

5. Situational Analysis

Sarvathrika Sahodarya Samithi as a charitable trust registered under the Public Trust Act 1961 with registration of

universal brotherhood in Kollam, popularly called S.S. Samithi. The institution aims at providing food, shelter, clothing, medication and proper care for the sick, poor irrespective of caste, color or Geed, region, language races or region.

Abhayakendram (homely shelter) under the auspices of samithi, is a homestarted in July 1998 at Mayyanadu about 15 kilometers from Kollam town. The patients discharged from the district hospital and other neglected mentally ill and physically handicapped people wandering in the street are given refuge here. S.S. samithi entered into the Social service for the upliftment of the downtrodden people in 1994. They started their activities at the District Government Hospital in Kollam where urgent attention was required for the poor patients left out by their family and relatives. They have come across various kinds of people suffering from different kinds of diseases they were brought from remote areas in the district. In beginning their activities were concentrated on providing free food to about hundred poor destitute patients every day and also decided to take full care for the people left out in the street and admitted to the hospital.

The major Aim and objective of this institution is rendering spiritual and temporal assistance and relief to those who are in need. They provide food, clothing, shelter and treatment for all the poor sick and needy people; it is their ultimate motto and sincere effort that street without fulfilling their basic right to line and the need of food, clothing shelter and medicine.

They have realized that most of the mentally disabled patients reaching the city from different states are either thrown out by the family or have become wanders due to their mental problem such mentally disabled patients couldn't remember either their place of origin or family. The inmates came here with extreme unhealthy condition due to lack of food, cleanliness and minimum requirements of clothing and toilet facilities under the auspices of the samithi a house of shelter, by the name "S.S. Samithi Abhayakendram" presently about 350 mentally disabled persons. Men, women and 13 orphaned children taken from the streets are given the best medical treatment and taken care of providing human assistance using the best methods of love, care and treatment. This they are made to feel homely life. From the total number of inmates who remained in the Samithi from the very beginning. The samithi was able to send back home about 400 persons fully recovered from illness and were to fully capable of teaching normal life in the society.

6. Functioning

The institutional care for the inmates is remarkable, there are 3 psychiatric social workers who worked as professional Social worker and 12 care takers for assistance, all of them were paid agents, they help the inmates to do their daily needs they had a vital role in their life, they were guided and practiced by these care takers. The institution was functioned in a systematic manner, the food section meditation, and prayer and recreation activities. The inmates are thoroughly, enjoyed the activities which they done

therethey were practiced under the instructions of these caregivers.e

The institution is working in all days (24x7) we can see an open office there without any walls, there heart were also open for the inmates, a humanity based institutional care which is almost same as a home there are three psychiatric social workers and four nursing staffs are officially placed there, they were present in the agency for 24 hrs except during their respective days of off. The inmates get their service at the time when they in need.

The care givers take care of these inmates they were worked in physical needs. The caregivers had a vital role in their life we can identify that the inmates were closely attached towards the care givers some of them were practiced with the instruction of these caregivers. Some were not; there we can see an emotional bonding in between the inmates and the care givers. They were interrupting in their physical and emotional needs.

There are permanent medical nursing staffs who were handle the pharmacy section they provide medicines and other medical assistance for the inmates and they were placed as the by stander when anyone get hospitalized. That much they involved in their work.

The institution have 350 inmates but the existing facilities are not enough for this much inmates. The room facilities and bed facilities are limited, most probably there are open halls where they accommodate with mats and pillows it is little bit unconvincing for us, because they cannot afford it with their daily income. The daily needs were mostly done through official and the unofficial sponsors. And also we can identify that they collect today's newspaper and recollect the details in obituary column and they send a consolidated letter for that particular address they send thousands of letters may be one or two will reply. That will be a great concern for this institution. This is one specialty which we identified here.

The daily food schedule is as follows: morning 7.30 am. Tea and breakfast, 1pm- lunch tea- 4.00pm, dinner 7.30pm at first the medicine will take then they serve food for the gents at first and then ladies. The food includes vegetables, non-veg egg and other nutrition's.

7. Nature of the inmates and the Recreation Activities

In this institution there are 350 inmates including gents and ladies, most of them were found from streets and some of them were referred from govt. Victoria hospital Kollam. The institution provides basic food, shelter, cloth and medical facilities for these inmates. All of them were totally or partially unfit by their mental and physical wellness. Each of them is unique in nature; each of them had their own identity as everyone has most of them had psychiatric medicines as sedations. So, the inmate feels a sedative mood every time. That will cause tiredness among these inmates. They were activity participated in any works there from the gate to the kitchen, they were settled with their job. That will create an active mood in their behavior; the inmates were busy and

engaged with their work, all these works were supervised by the care givers. They were worked with their instructions. We cannot say that all of them are perfect not at all but they give their best with in their limitations.

The afternoon section after lunch 2.30 to 4.30pm this is the time section where the recreation activities has been done, during this time all the inmates were clubbed in a hall and they were actively participated in these activities, such as reading newspaper, singing, Dancing and playing games. One of them were loudly read the newspaper, probably current days newspaper, which share news around the world then the section of song, there are number of singers there, and they dancing, they are moved with the Rhythm of music this section is very active in nature most of the inmates choose this time for their platform they just do what they want the gaming section also, we know these inmates can't do things like a normal man, they have some specialty with their mind and behavior, for that, there are limitations for them they play the games such as passing the parcel and musical chair the main motto is to calculate the capability of concentration of mind among these inmates, these kind of sorted games will help for that the time of recreation activities they feel free and comfortable. This institution allowed this recreation time for a hidden purpose that we identified that, the wont allow the inmates for the day sleep, which leads them awake in the night.

Family care giving in mental illness

Family is the primary institution which provides basic education and knowledge for everything as it like family had an important role in mental illness, a person who is mentally retarded is firstly cared by the family. Families can play an important role in supporting a loved one with a mental health or addiction condition. Family members often deal with crises, assist with system navigation, encourage and support treatment, secure housing, arrange for income assistance, monitor symptoms and maintain records of previous treatments medications and hospitals.

People dealing with mental health and addictions conditions in their family can initially not have adequate information regarding the problem, treatment or available resources. Over time, they may feel that they are not adequately regarded for their knowledge of their family member and contribution to the mental health and addiction system. This situation is beginning to change as more family to family support becomes available and service providers more actively involve families in planning to improve the navigation and quality of the mental health and addictions system.

8. Findings

The study provides a detailed description of the importance of care givers in mental illness in an institutional setting and family setting. The study focused upon the situational settings of Mayyanadu S.SSamithy charitable trust. Mentally disabled persons are isolated from the society the social attitude towards them is different. The care givers had a great role in their life from family member to a paid agent they were emotionally attached towards them. A mentally

disabled child is closely attached towards his or her mother or father or sometimes the one who cares him most he needs him for his daily needs, like this every care giver had a role in each inmates life in this institution too. The institution provides basic needs for the one whom in really need. The caregivers had a vital role in character determination. As we all know that each patients are unique in nature individuals have inherent worth and dignity. Here also the institution provides individual dignity for each inmate.

Caregivers for people with a mental illness experience distinct issues which often put extra pressure on the relationship between the caregiver and formal care services that may be supporting the recipient. Relationships between the caregiver and recipient may require continuous adaptation due to fluctuations in the psychological state of the recipient.

Caregivers' sense of control over their lives, their feelings of being burdened, the degree to which their social life suffered, competing responsibilities, insufficient time for themselves, feeling their health had suffered and that caregiving had affected their social relationships. Social workers with the individual, family and community in the context of the person's total life situation. They may offer individual or group counseling. The social worker ordinarily serves as liaison between the treating agency and the family.

Generic tasks of care-giving included:

- help with personal cares, including dressing, bathing, toileting
- help with mobility, such as walking and getting in or out of bed
- undertaking nursing tasks, including administering medication or changing dressings
- escorting the recipient to appointments
- supervising and monitoring the recipient
- providing emotional support
- being a companion
- undertaking practical household tasks, including cooking, shopping, housework, and
- Help with financial matters and paper work.

Caregivers of people with mental health problems may also need to:

- keep the recipient safe
- deal with socially unacceptable or aggressive behaviour
- prompt the recipient to undertake personal hygiene
- ensure medication is taken on time
- ensure the environment is appropriate
- liaise with health and other professionals
- educate family and friends

9. Suggestions

Following strategies and activities that are necessary for strengthening special care services,

- Development of community based mental health services and psychiatric units at general hospitals.
- Integration of mental health services in primary care.
- Equitable access to appropriate assessment and treatment of physical health conditions

- Development of the psychosocial network
- Development of specialized institutional services for those with more complex needs.
- Training of mental health staff.
- Fighting against stigma and social exclusion.
- Support to families: Specific measures should be developed to support families coping with problems associated to the longer term mental disorder of their beloved ones.
- Participation of service users and care givers in all aspects of care.
- Enhancing services and support for families
- Involving families as partner in care ,rehabilitation and recovery
- Involving families as system partnersand provide a voice for families in decision-makingby including family representatives on mental health and addiction organizational boards andcommittees.
- Provide more care for the needy people especially those who need special care and protection or affecting chronic mental disorder
- Create a half way home for normal persons
- Education can help families develop successful coping strategies and enhance their contribution to the recovery of their loved one.
- Enhance social care facilities: visiting and entertainment, taking for drives, acting as conduit to the social world outside residential care
- Encouragement to employers to allow more flexible and family friendly employment conditions to the care givers.
- practical support for caregivers (such as equipment, or training in safe lifting techniques)

10. Conclusion

Mental health disorders are a common occurrence in every society, and affect people of all ages, gender and socio-economic status. Mental health problems and illnesses can have a considerable effect on families and relationships, with issues such as a lack of diagnosis, treatment use and efficacy, chronicity and propensity all impacting on a family's experience of mental illness. There is a need for more health intervention strategies to mobilize families, make them aware of mental health and ill health. Health institutions need to involve community members in mental health awareness programmes, and encourage their active participation. Empowering individuals by helping them make the most of available sources of social support, providing assistance with coping strategies and enhancing feelings of mastery or self-efficacy may be particularly worthwhile for some caregivers, but are not currently part of mainstream services. There is a sudden need for interventions from government to look into this matter and should start family based and institution based schemes and programmes for mentally retarded children. A number of welfare programmes have been started for the mentally handicapped individuals by the govt. and voluntary organizations but families of these handicapped children have been ignored. The intervention measures should not only be directed towards handicapped person, but also towards his family as well which also suffer to a great extent only then there will be change of viewpoint about care of such people.

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