



Caring the disabled due to mental illness has different meaning

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INTRODUCTION

Caring the disabled due to mental illness has different meaning to different carers who may be Parents, siblings, husbands, wives or even a distant relative. I write this from the perspective of a parent carer located in India.

When my only daughter started showing early signs of the disease for us it was a case of disobedience first and so the normal punishment of not allowing her to watch TV or play games was given but the rebellion only increased and we just could not understand what to do. Soon it deteriorated so rapidly that she became totally abnormal. That is the time we have to take her to a Psychiatrist in the local district hospital. By telling a lie, who gave us "Serenace"¹ tablets as initial treatment. But the very same night she became violent for the first time. This completely disoriented us and we decided to take her to Delhi for treatment. There for the first time the word Schizophrenia was used and we could not even spell it properly. A frank appraisal was given that this is an incurable disease and we can only expect "socially agreeable behaviour" after months of treatment. We the parents could not accept that our 12 year old girl could be having such a disease. So the search started for various Psychiatrists in India and after that various treatments from Ayurvedic to Homeopathic and to finally Allopathic treatment. This also made us realise that for the first time that Psychiatrists do not take house calls and taking a patient to the Psychiatrist is itself a big problem where superhuman effort is required. Tying the patient with ropes is normally employed by villagers in India. Sometime this is frowned upon by Human rights activists who do not understand. Keeping patients locked up in a house or room also frowned upon by these human rights activists who do not offer solutions especially even ambulance was not provided. Now this problem is solved in many states.

We finally landed up NIMHANS² in Bangalore one of the premier institution, after my sister suggested it. The indoor treatment and the stay at NIMHANS made us realise various type of mental illness and even amongst Schizophrenics the rate of coming out of the shadows varies with individuals. We also found there is also a discipline called Psychiatric Social Worker. It is here I found a patient may be asked to do candle making, baking cakes, carpentry to gain his own self confidence. Soon I started hearing the word "disability" "rehabilitation" etc. Then I found about rehabilitation centres run by Richmond Fellowship, Medico Pastoral Association, Atma Shakthi Vidyalaya etc. I relocated to Bangalore as I faced 3 relapses during this time due to my negligence and also due to the cleverness of the patient who could cheat us by not taking medicines. One also finds friendship amongst the families and also learns from their experiences. The Erawady fire³ and how this brought into focus the problem of disabled due to mental illness

Soon I found it is important to get disability certificate for Income tax benefits, railway concessions and also for pension from Government from my pension account but due to various reasons the Psychiatrists did not make a scale for evaluating the disability of mentally ill patients. Thought the law The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995⁴ was passed in 1995, the actual scale for evaluation of disability was framed only in the year 2002 called IDEAS⁶ (Indian disability evaluation and assessment scale). I may be the first one in Karnataka to get the evaluation done in the local medical board at Victoria Government hospital. NIMHANS started doing the evaluation much later as they had lot of ego issues. The evaluation of the Medical board and its assessment alone is not enough. One has to submit the same to Disability Commissioner who actually issues the Disability certificate normally for 5 years. The IDEAS scale itself prepared by the Psychiatrists does not address the problem of rehabilitation of disabled due to mental illness. The Psychiatrists view of cure prevails here. For them a patient who never used to take bath or become violent sometimes has started taking bath occasionally or putting flowers on her hair is a great progress clinically. That the patient does not work and only eats popcorns and drinks lots of Pepsi in front of TV and sleeping most of the time is not something

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which is addressed in a proper way as the rehabilitation requires the patient comes to a level to work. If the patient does not work then he or she should be treated as disabled even though clinically he might have progressed as per the professionals. This issue is known to the Psychiatric Social Worker who has no voice in evaluation.

Form for railway concession has to be procured from Railway office and those forms do not have column for disability due to mental illness. So the form for mental retardation has to be used which is valid only for 3 years. The pension authority requires different certificates while the Income tax authorities require another one. The present NDA⁷ government has already said they will issue a uniform disability card linked to Adhar card but then the bureaucracy works slow and nobody cares.

The case of Rehabilitation council⁸ which was established in 1992 never to have a specific Rehabilitation centre for the disabled due to Mental illness till now shows how much the Government of India and those responsible for rehabilitation of the disabled understood the problem. Recently an effort is being made to start a Centre for rehabilitation for disabled due to Mental illness at Bhopal which may take ages to come up as is the normal case.

The FUNDAMENTAL QUESTION WHICH BOTHERS MOST OF THE CARERS IS AFTER ME WHOM? WHAT? By the way My cancer is not responding to treatment and doctors have advised me to stop chemotherapy. I am living on prayers and good wishes of all. My wife is a stroke patient and caring for two of us is a real exercise for her. I have not reached the stage of pain management. This was to be addressed by the first NDA Government which had Mr. Arun Shouri who himself is a carer of a Mentally retarded child as an influential Minister. The result is the National Trust Act 1999⁹. But unfortunately due to powerful lobby groups from mentally retarded the whole act was restricted to mentally retarded and Autistic children. Soon the powerful lobby in the guise of prevention of disability included learning disabilities as part of mental retardation which inflated their numbers in the Census figures. Now the group controlling the trust has included only those disabled who are 80% disabled after lot of noise which the IDEAS scale normally may not be possible. Any person who is mentally ill and being treated as outdoor or indoor patient for more than 5 years and who do not work should be treated as permanently disabled with 80% disability for inclusion in the National Trust act.

EDITOR'S NOTE

This is a voice of a caregiver which gives us a first hand account on various aspect of caregiving experiences. When any member of the family getting affected by Schizophrenia first time, usually the relatives do not know what is wrong or what to do. They observe the abnormal behaviours and may consider it a passing phase and may attribute it generally to various megico-religious cause or addiction or other explanations but do not consider it as an illness. Before accepting it they can experience

or express various emotions or issues fears and anxieties, guilty, blamed, frustrating, stigma, violent, anger, stress, expressed emotions, burden, lack of social support, bargaining, depression and acceptance.¹⁰ Low or lack of knowledge about illness and medication/treatment make the condition more critical. Long chronic course of illness makes caregiving more and more tedious some time they lose the hope completely. Caregiving needs tireless effort, energy and empathy, and indisputably, greatly impacts the daily lives of caregivers. There are physical, social, emotional, and financial impacts of caregiving.¹¹ Caregivers are at risk for various different physical and mental health challenges. They neglect their own care and may suffer from poorer immune function and have more chronic illnesses and have higher mortality rates than non-caregivers of the same age.¹¹⁻¹²

In a contrary to a general caregiver, Captain Johann is well aware of various issues and happenings associated with many organizations, care givers associations in the field and actively participating in various programmes and activities pertaining to caregiving he also voiced various issues and advocated for the same in various national forums.

Our sincere appreciation for his contribution along with prayers and good wishes.

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