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Involving Patients, Carers & Families in the Treatment Programmes for the Mentally ill

Despite the general acknowledgement of the popular slogan that “there is no health without mental health”, mental health disorders continue to increase and cause considerable suffering all over the world. There is growing evidence that at least 20-25 % of the general population will have some type of mental health problems that may require help, support and management at any particular time. The public health impact of mental disorders is profound as the estimated disease burden and disability attributable to mental disorders have been very high.

However mental health problems not only affect the sufferers of mental illnesses alone, carers and family care givers also share the burden of these illnesses. The stress of caring for the mentally ill is quite challenging and living with someone with severe mental illness is equally stressful. Likewise many family members do not have the knowledge and skills necessary to take on the responsibilities of care giving and are thus unable to cope with the considerable amount of the caring roles and responsibilities.

The carer’s difficulties may vary from one country to another but it assumes a significant importance within the Asian culture where a strong emphasis is placed on family ties and family responsibilities. Whereas most of the Asian families prefer taking care of their mentally ill relatives at home, caring may increase their negative experiences of care giving with additional burden of disruption of family routine and interference of their day-to-day functioning. Stigma likewise comes as an added burden and having a negative label of living with a mentally ill increase further emotional distress. At many places the majority of family care givers or family members who are involved with the treatment and management of the mentally ill are elderly members of the family. This certainly increases the level of burden with additional worries that no-one would take care of their patients when they are too old or after they die. Similarly there are reports that women are more likely to be the care givers in many parts of the world. World Federation of Mental Health in their report in 2010 estimated that globally around 80% of the care givers are women, they could be mother, wife

or daughter of the patient and are usually with low income support. These issues become even more important in countries where there are not enough state run facilities for the treatment of the mentally ill along with limited options for support to the family members.

While there is an increasing acceptance that family assumes the primary and long term care-giver role and an important resource for patient’s well being, there is a strong need for exploring ways and means to provide help and support to the families and carers.

- A number of programmes are recommended for involving carers and families in the treatment programmes. Psycho-education, a strategy of teaching patients and families about mental disorders, their impact, their treatments and personal coping techniques and resources to overcome illness related difficulties, is highly recommended as a tool in supporting and helping the patients and the care givers. Psycho-education can have many descriptions including family therapy, family education programmes, family led support groups and individual consultation and specific psycho-education sessions
- Promoting the establishing of local carers groups is another way of supporting carers and families as there is ample evidence that working with carers and families is not only beneficial for short-term outcomes but may also lead to long-lasting improvements in service provisions.
- Growing interest among professional organisations for supporting families and carers has also raised the profile of this aspect of care. World Psychiatric Association, the umbrella organisation of psychiatrists, has raised this particular issue by issuing guidelines to its member societies on developing partnership for best practice in working with service users and carers.

It is expected that civil society will also join professionals in their efforts supporting the carers & making a visible change for the care of mentally ill that certainly remains a neglected area in health and social care systems in many countries. □

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