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Family carer education in mental health

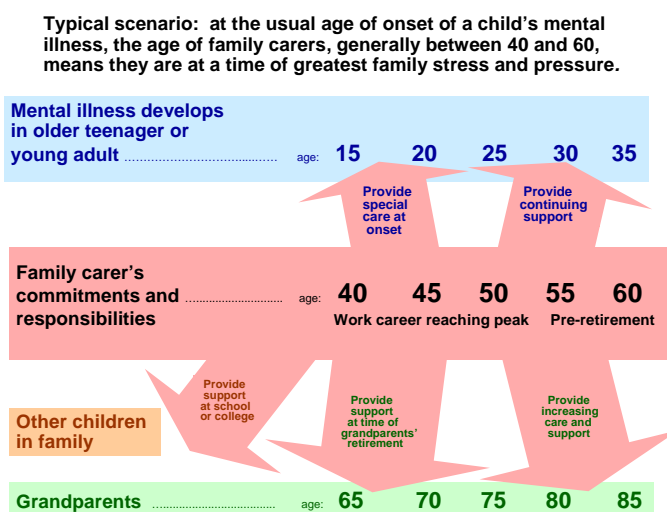
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The purpose of this briefing paper is to set out the reasons why it is so important that families and carers of persons suffering from mental illness become empowered through the medium of quality education. The paper focuses on what needs to be done to make this a reality and contains a number of recommended actions.

It is a widely accepted fact that the majority of people who care for persons affected by mental illness are family members. So, when the word "carer" is used, it really can be interpreted in the majority of cases as meaning a family member. This is an important fact and the result is that the majority of carers live with the illness 24 hours of the day, each day of the year (1). As the result of a survey conducted in a number of European countries, it was reported that caregivers of adults with mental illness spent an average of 6–9 hours per day providing care (2). Another survey carried out in the United Kingdom found that 95% of carers are members of service users' families and that 29% provide support and care for more than 50 hours per week (3).

Given their proximity to the condition, the carers of persons suffering from mental illness unquestionably play a key role in their care and in supporting their pathways to remission and recovery. Apart from the pure emotional support given by carers, there are also many examples of practical support, such as cooking and other household chores, assisting in keeping medical appointments and giving financial support; 40% of carers feel that they provide support on a daily basis. A recent survey by the European Federation of Associations of Families of People with Mental Illness (EUFAMI) shows that the typical carer has been caring for an average of just over 13 years (4).

To illustrate the situation of families, it is beneficial to set the scene by examining the environment in which they, especially parents, find themselves during a first episode of a mental illness in a family member (Fig. 1 across). At the typical age of onset of an adolescent or young adult's first episode, the average age of the family carers, usually parents, is between 40 and 60 years. At this stage of life, they experience high levels of family stress and pressures resulting from normal family living. As they attempt to cope with their family member's onset of illness, they are most heavily burdened by other major family responsibilities, such as other children attending school or college and retired or elderly grandparents, as well as career and financial worries. Other notable statistics related to family caregivers show that 82% are female (mothers, in 90% of cases), 70% are over 60 years of age and 33% are over 70 years (5). Moreover, the perception of burden may vary between different cultures in terms of being more or less accepting of disability and of seeing hope for the future (6). Hence, there is a clear need for support and training for such families.



Carers and their families and friends have needs of their own. While caregiving can be a strongly positive experience, most who write about it describe its impact in terms of burden, both subjective (perceived) and objective (for example, ill health, economic implications, disruption of daily routine). In the study mentioned above (3), it was found that 90% of carers are adversely affected by the caring role in terms of leisure activities, career progress, financial circumstances and family relationships; 60% of carers have a significantly or moderately reduced social life; 33% of carers find that family relationships are seriously

affected; and 41% of carers have significantly or moderately reduced mental and physical health.

Despite their important role, carers frequently feel undervalued and unengaged by the health care system. Again, quoting from a recent EUFAMI study, almost 60% of respondents stated that they felt unrecognized by the professional health care team (4,7,8). Although there is no doubt regarding the important role that families play, they have frequently felt unengaged by health care services and that their own needs have been neglected. It should be evident that support and assistance are among carers' most important needs (9).

The rationale for addressing the needs of families/carers is two-fold. Firstly, carers play a key role in supporting patients towards remission and recovery (4). Secondly, since the families are themselves subject to distress, it is also logical that they should receive support and assistance.

Families are a primary care-giving resource for adults with mental illness, yet they often lack the knowledge and skills needed to assist their relatives (10,11,12,13,14). Studies show that families routinely request information on basic facts about mental illness and its treatment, behaviour management skills, and the mental health system in order to better cope with their relatives' illnesses (15,16,17)

Evidence supports the value of family initiatives in the early stages of psychosis. Families of persons in the early stages at the onset of mental illness are in a unique position to be able to recognize emergent symptoms of psychosis and encourage early contact with medical services. In fact, carers frequently play a key role in bringing such persons to the attention of health care professionals

However, the ability of families to recognize early signs and symptoms is dependent on their level of knowledge. Education campaigns for the general public aim to increase awareness and so facilitate early identification by family members. There is now good evidence that such educational campaigns aimed at the general public (including families, friends, teachers and police) can shorten the duration of untreated psychosis (18,19,20).

A body of evidence exists, which supports the need for family interventions in chronic mental illness. A recent analysis supports the implementation of family therapy to reduce relapse rates – typically, relapse is approximately halved. Family interventions reduce the burden on carers, lessening their distress, improving the carer–patient relationship and overall family functioning (21,22,23).

Studies of family-led programmes suggest that these interventions may increase participants' knowledge of the causes and treatment of mental illness and improve their ability to cope with illness-related problems (24,25,26,27). In an early evaluation of one such programme, respondents reported that, as a result of taking the course, they increased both their knowledge of the causes and treatment of mental illness and of the mental health system (26). From an evaluation of another family programme, it was reported that there was an improvement in overall knowledge about mental illness and the treatment system. These knowledge gains were maintained six months after programme participation (24).

Participation in family-led education interventions, such as the Prospect, journey of hope programme and the Family to family programme, provide families with much of the information they need to better cope with their relatives' mental illnesses.

In countries of western Europe, the movement from treatment in large mental hospitals to treatment in community mental health facilities has resulted in a heavy burden of care for the families of people with mental illness (28). The nature of this care-giving role is often not understood by professional mental health workers. Families are frequently excluded from treatment and care plans. Reasons for this include the belief that the individual has the right to a confidential relationship with his doctor. Mental health professionals are trained to maintain confidentiality. This can assume precedence over other treatment and care issues that may be of greater benefit to the patient (29). Secondly, mental health professionals are not skilled in working with families. Some recent programmes now train mental health workers to provide families with the skills needed to be active, positive carers rather than passive victims of the difficult situations created by a relative's illness (30).

The relationship between families and mental health professionals is different in eastern European countries where families have never been excluded from the treatment process and are the mainstay of care for their relatives with mental illness. Confidentiality is not a problem, although stigma is even greater than in western European countries. Nevertheless, the natural potential of families to facilitate recovery in their ill relative has generally not been recognized. In developing countries, families have a major role to play in the resocialization and the training of the ill person in vocational and social skills, not only because of the close family ties that exist in these traditional societies but also because of the lack of professional staff to deliver these services. The burden of care is further aggravated by issues of poverty and illiteracy (31).

Regardless of whether the country is in the developed or developing world, there are too few instances of families receiving the information, education, training and emotional support they need to facilitate their loved one's recovery.

Recognizing the care-giving roles of families and their need for knowledge, numerous treatment guidelines recommend psychosocial interventions to educate them about the causes and treatment of mental illness, coping strategies and community resources (32,33,34,35). Participation in one such intervention has been found to increase the knowledge and coping ability of families (36,37,38).

Health and social care professionals have usually been trained through a combined academic and apprenticeship system. They have all been trained in patient care in clinical settings, often at the bedside or in clinics and general practices. Thus, the role of patients in the training of mental health care and social service professionals has always been limited and that of families even more so. However, the role of the latter has always been an inactive one.

Also, a part of the medical community has always been somewhat uneasy that patients and carers could be exploited if they were used to assist in educating health professionals. However, this is offset by carers in particular who point out that they have a unique understanding of the illness and feel that they should play an active part in teaching. Research shows that supporting carers benefits service users by enhancing the effectiveness of service delivery, decreasing hospital admissions and reducing relapse rates.

A change is beginning to take place whereby carers, along with the persons affected by mental illness, are becoming actively involved in the training of medical professionals, thus benefiting the professionals, the families and the service users.

Policy recommendations

The following are some suggested actions/recommendations that are based on positive evidence found in research. They have not been prioritized and appear in no particular order.

Policies need to be developed to ensure that families are not taken for granted and that the value of their role is recognized. A clear demonstration of this would be the involvement of family representatives in the development of mental health policy-making. Also families should be actively involved in the design, planning and implementation of mental health services. Families should also have the opportunity to be actively involved in the planning and review of family support and care services. In simple terms, give caregivers a voice – a platform – to allow them integrated representation.

Strategies to improve support and training services for carers need to be developed. Also procedures need to be put in place whereby "unknown" carers can be identified and brought into the system so that their needs can be assessed and the necessary support and education provided. Education and training packages, which teach families and carers about mental illness and its management and help to build coping skills and resilience, are required. In order to develop and implement such programmes, for example, the Prospect, journey of hope programme and the Family to family programme, the allocation of financial support by public authorities is urgently required to establish and support the operation of peer support groups. National proactive awareness programmes outlining the benefits of family involvement and the reasons families need to be involved should be developed and implemented. Empowerment happens through the individual but the surroundings (policies and strategies) have to be supportive and encouraging. It is, therefore, not limited to contact between professionals. An atmosphere, which encourages empowerment, is also visible in the way in which those involved deal with each other and in the interactions between the management and all involved (39).

A major strength of family members is their intimate knowledge of the person with the illness and what they have learned through a process of trial and error. Caring for someone with a mental illness exacts an emotional toll. Family members are affected by depression and anxiety to a much greater extent than is recognized. These symptoms reduce the capacity of the family to support the patient. Professionals need to be trained to understand and recognize this fact and to be able to provide information to families in order to help them cope with such challenges. Family members experience loss of hope and expectations for their sick relative. They also feel that the person they know has been changed by the illness. Their grief needs to be acknowledged. They need help in coming to terms with both these kinds of loss. This is something, which must be incorporated into family support and training programmes.

Countries should have employment legislation to cover the needs of family carers. The welfare benefit systems across Europe need to be revamped so that families are compensated to offset the negative financial implications of being family carers, such as loss of earnings. Strategies are required, which will improve the interaction between carers and public bodies and focus on families as partners in care. Policies that will support family members in combining care-giving and work – and that include the provision of flexible services to support working carers – are critical.

Relatives have gained a great deal of experience and have much to teach the medical community. Their expertise should be acknowledged and valued. Families should be involved in the education and training of medical staff working in mental health services. The involvement of carers in mental health training is a beneficial development for service users and professionals but one that requires further work. From the limited amount of feedback that

is available on this topic, it appears that where families have been involved in the training of professionals, the latter have more positive attitudes towards the families, use less jargon and become more optimistic regarding patient recovery. Families and carers, on the other hand, are empowered, have better relationships with the mental health professionals and enjoy much more personal satisfaction and an improved quality of life. Attitudes change dramatically and everyone benefits, especially the person with the mental illness. Barriers begin to fall.

Family members may have different expectations, some of which may very well be unrealistic. However, they cannot or should not be dismissed. It is important that they are acknowledged by the care team and that the various family members are engaged in a realistic goal-setting strategy so that they can become a productive and beneficial "cog" in the overall treatment programme of their loved one. This in turn will help the person with the illness to hopefully return to the highest quality of life that it is possible to attain after a mental illness.

An introductory education programme is an effective way of engaging families but needs to be followed by continuing education throughout the period of treatment and care. Each family has its own concerns, which need to be addressed. In addition, clinicians should recommend that the family participates in a support group. The provision of relevant and high quality information to families and carers, for example, on how the mental health system works and about different mental illnesses, treatments, etc., is key to the maintenance of an efficient family environment.

Families also need to understand what can happen in the event of a relapse and know what to do. Again, proper information and planning is essential. It is essential that the family is supplied with the name and phone number of the person who will deal with any future enquiries. When families have received training in this area, it is far more likely that they will be able to recognize the early indications of a relapse and alert the medical personnel a lot sooner than if they had not, and this can be of immense benefit.

Quality communication is critical. Whereas carers cannot always judge whether treatment is good or bad, they certainly can recognize good communication. Carers value good communication and the provision of adequate information about the illness, its treatment and accessing health care services is a key priority. In some families, members find it difficult to communicate because they stop listening to each other. Simple ground rules for clear communication are necessary as well as support to allow families adhere to them. The concept of triad (which is beginning to happen in some European countries and involves the person with the illness, the family member(s) and the medical professionals actively working together) needs to be more widely accepted and promoted across the various countries.

When mental illness "enters" the family circle, family members tend to remove themselves from their natural support networks for a number of different reasons. Initially, they benefit from social interaction through relatives' support groups or multifamily problem-solving groups. It is important that the caring role does not absorb all of their lives and that a balance be maintained. Plans allowing families to lead "normal" lives, such as integration into the labour market, participation in society, etc., need to be developed. This type of planning needs to include representatives from the local community groups and local public authorities as well as from commercial and trade bodies. Recreational activities should be promoted that are likely to lead to shared enjoyment by family members.

In his novel, "Anna Karenina", Leo Tolstoy, the famous Russian writer, wrote: "Happy families are all alike, every unhappy family is unhappy in its own way". The empowerment of families is a starting point for more happiness for all of those affected by mental illness.

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