

SHORT REPORT

CARERS AS TEACHERS

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Abstract

Objectives: This paper reports the outcome of Session With Carer, one of the activities in the Year 4 Personal and Professional Development (PPD) module in the new integrated curriculum of the Undergraduate Medical Programme at the Faculty of Medicine, Universiti Kebangsaan Malaysia (UKM). **Methods:** This activity involves groups of 14 – 15 students sitting in with family members of individuals with mental illness. The session starts with the carer giving his or her perspective of patient's care and the challenges involved. This is followed by a question and answer session. Finally, the carer provides a written feedback by way of scoring certain items as well as brief comments. After the session, each student is required to prepare an individual report in the form of reflective writing. **Results:** Out of a total of 224 students, the reflections of 126 students were reviewed to assess what they had learnt from the Session With Carer. Among the more significant findings were: 100% learnt about the various challenges faced by carers. 31.7% learnt the importance of faith/spirituality of the carer in caring for a mentally ill family member. 29.4% learnt the importance of family and others' support. An equal number, that is, 26.2% learnt that it helps for the carer to have good mental health and a positive attitude, as well as good knowledge of the illness. Those who became aware of the benefits of the carer having patience and determination made up 23.8% of the total reflections reviewed. **Conclusion:** The findings show that the Session With Carer is very educational, and helps create more awareness of the importance of the carer's role in patient management and support. In other words, carers can act as teachers in creating more public awareness about mental illness and ultimately, help in gradually removing the stigma associated with mental illness. Therefore, carers should be utilized for this purpose.

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Introduction

A carer is someone who looks after or supports another person who needs help with their daily life due to age, long-term illness, disability, mental health problems, and/or substance misuse [1]. A carer does not receive payment for the care they provide [1]. The term 'carer' does not include individuals who work as volunteers on behalf of a voluntary organization [1]. Carers can be family members that include children and young people, who live with the person they care for, or family, friends or neighbours who live elsewhere [1]. In this report, we are looking at carers (i.e. family members) of mentally ill persons in particular.

The shift in locus of care for people with mental illness from hospitals to communities has made families increasingly pivotal and central in the care of their mentally ill relatives [2]. The carers' intensive exposure and experience in caring for their mentally ill relatives make them very good resources for understanding more about mental illness, the mentally ill person and living with the mentally ill.

Going back to the turn of the 21st century, the important role of the carer was already being recognized. In the United Kingdom, the Patients' Forum, INVOLVE, and the Commission for Patient and Public Involvement in Health all exist to ensure that patients

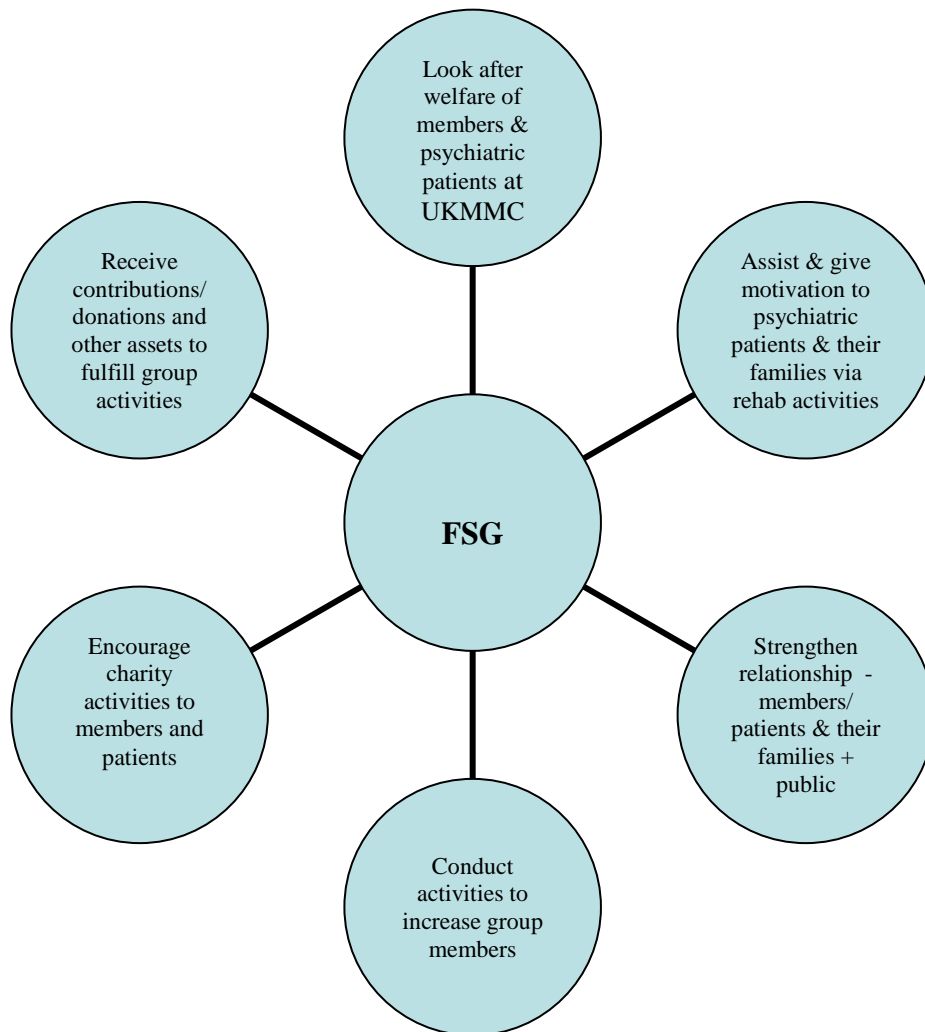
and carers are involved with both the academic and clinical side of health care [3]. In Australia, the National Standards for Mental Health Services' guidelines on mental illness strongly recommend involving carers and developing partnerships with families of patients [4]. Even in Malaysia, families' involvement has been a key feature for management of the mentally ill [5].

The primary reason for involving service users in the training and education of mental health professionals is the anticipation that it will produce practitioners capable of delivering improved and more relevant outcomes for users and their carers [6]. A nursing school in the United Kingdom took steps to promote greater service user and carer involvement in order to further develop mental health education [6].

One way the role of carers has been given recognition in Malaysia is via Family Support Groups (FSG). In 2002, initiatives to formalize and develop the FSG started in Johor Bahru and until the end of 2004, about 16 FSGs had been formed throughout the country with a total of 1084 carers [5]. Training for FSGs was carried out using a module developed in 2002 [5].

At the Community Psychiatry Unit in UKM Medical Centre, FSG was formed in 2002. Its aims are depicted in Figure 1 below:

Figure 1: Aims of Family Support Group at UKMMC



Methods

A Family-to-Family Education Course that comprises 10 sessions is conducted for families that have mental patients. It is a clever cooperation/sharing between families and health staff whereby both

parties use their own expertise to ensure the success of this course. The course comprises the learning of two skills (problem solving and effective communication), as well as care, emotional support and empowerment.

Since its conception, 4 batches of families have graduated thus far with each batch made up of 10 to 15 families. The dropout rate is low, only about 10 to 20%. As a result of going through the course and being part of the support group: families are more united; they feel more emotionally supported; helps them deal with their grief; and they advocate for other carers.

Session with Carer

As part of the new integrated curriculum of the Undergraduate Medical Programme at the Faculty of Medicine, UKM, there is a Personal and Professional Development (PPD) module. It functions to further facilitate the development of professionalism in clinical work of medical students as part of the preparation to become future clinicians.

When Year 4 medical students undergo posting in psychiatry, one of the activities in the PPD module is the Session With Carer. This activity involves groups of 14 – 15 students each, sitting in with family members of individuals with mental illness. The one-hour session starts with the carer giving his or her perspective of patient's care and the challenges involved. This is followed by a question and answer session. Finally, the carer provides a written feedback by way of scoring certain items, which are, professional behaviour, group participation, communication skills, and empathy, as well as brief comments. After the session, each student is required to prepare an individual report in the form of reflective writing.

Four carers were chosen from the FSG, with one of them being the president of FSG. They were chosen based on their amount of experience and level of acceptance regarding their family member's condition. In other words, these chosen carers had already very much accepted the circumstances. The carers chosen had been living with and caring for a mentally ill family member for many years. One even had to care for 2 mentally ill family members. It should also be noted that the mentally ill family members in this case were immediate family such as spouse and children.

For the academic year 2008/2009, a total of 224 Year 4 students underwent posting in psychiatry. They came in 4 batches throughout the academic year (which is an average of 56 students per batch). Each batch was further divided into 4 small groups, and each group was assigned a carer. It should be noted that the same pool of carers were utilized throughout the academic year, meaning each carer sat with 4 groups in total.

Out of a total of 224 students, the reflections of 126 students (which is slightly more than 50% of the total number of students) were reviewed to assess what they had learnt from the Session With Carer. This was due to the fact that the remaining reflective writing reports could not be located.

After going through each of the available reflections, the author came up with 26 categories or points that the students had learnt. It should be noted that each student had learnt more than one point from the session.

Results

who had mentioned them in their reflections are listed in the table below:

The points learnt from the Session With Carer and the percentage of students

Table 1. Points learnt from session with carer

Points learnt	Percentage (%) of students
Importance of community awareness about psychiatric illness	14.3
Importance of communication skills between doctor and patient and doctor and carer	11.1
Importance of communication skills between family and patient	3.2
Importance of motivation from doctor to carer and patient	0.8
Various challenges faced by carers	100.0
Importance of support for patient from family and others	29.4
Family’s management of patient	3.2
Importance of good mental health and positive attitude of carer	26.2
Importance of faith/spirituality	31.7
Family is precious/appreciate family	3.2
Importance of support for carers	19.8
Value doctor spending more time with patient	0.8
Importance of biopsychosocial aspects of management/holistic management of a mental disorder	11.1
Therapeutic relationship between doctor-patient and doctor-carer	7.1
Benefits of having patience and being determined	23.8
Importance of knowledge	26.2
Benefits of patient socializing with the community	1.6
Varied presentations of schizophrenic patients	0.8
Benefits of love	11.1
Good insight of patient and carer/family	1.6
Importance of carer in patient management	10.3
Role of complementary medicine and doctor’s stand on that matter	4.0
Being over-protective/over-involved does not help	1.6
Importance of maintaining good family relationships	3.2
Importance of carer maintaining a normal life and having good coping skills	3.2
People with mental illness can lead normal lives	0.8

From the table above, the most significant point learnt is regarding the various challenges faced by carers (100%). This is not surprising as the carers were required to talk about the challenges they face in caring for a

mentally ill family member. Positively speaking, it is good to note that the carers did not overlook this area, and even if they did, the students obviously questioned them about it during the question and answer session.

Falling far behind but still considered significant is the point on the importance of faith/spirituality (31.7%). It should be noted that all the carers who participated in the Session With Carer are Muslim. Hence, the tendency to fall back on their faith is strong. They believe that whatever happens is for a reason, and if that is what God wants them to go through, they will accept it willingly. This is not surprising considering that a lot of research have shown that people caring for an ill family member turn to religion for support. Family caregivers of persons with serious mental illness often turn to spirituality for support, and religiosity may be an important contributor to caregiver adjustment [7].

Following closely behind in terms of significance is the point on importance of support for patient from family and others (29.4%). This point rings true in all the carers' experiences. For example, a supportive environment had enabled one of the carer's mentally ill son to work.

An equal number, that is, 26.2% learnt that it helps for the carer to have good mental health and a positive attitude, as well as good knowledge of the illness. In terms of having good mental health and a positive attitude, it was fortunate that all carers were healthy, mentally and physically, while their positive attitude can be related to having strong faith. All the carers were educated persons and motivated to learn more about the illness that their family members had. One carer, in particular, kept stressing on the importance of knowledge several times during the session.

Highlighting the last of the significant outcomes from the Session With Carer, 23.8% of the students became aware of the benefits of the carer having patience and determination. This point links up with having strong faith and a positive attitude. Having patience and determination resulted in these carers' mentally ill family members showing progress in some way or another. One carer reported that she was very proud of herself for having succeeded in taking care of her mentally ill son, more so that he had no history of psychiatric admission.

Discussion

Carers do play an important role. Families, in particular, have many strengths and resources which include: (i) the development of an optimal emotional and social atmosphere; (ii) the provision of information on a very wide range of issues; (iii) protection of their mentally ill relative from adverse community responses; and (iv) personal connections which they can use in the person's rehabilitation [8].

As has been seen from the outcome of Session With Carer, carers can function as teachers or educators to different groups of people such as other families, medical practitioners and health staff as well as students in various health-related fields, and the general public. This echoes what had been suggested previously, whereby among others, it was put forward that family carers and consumers can become educators and trainers of mental health professionals, as well as of other families and consumers [8].

Based on the outcome of the Session With Carer reported in this paper, it is clear that students viewed this session and sharing experience positively. Feedback following participatory workshops involving users and carers, together with university academic staff and students has been highly positive, especially feedback from students, with an appreciation of user and carer perspectives [6]. Joint monthly workshops at Southampton University involving medical, nursing, social work, occupational therapy and physiotherapy students with carers of terminally ill relatives or people who were recently bereaved (almost similar in concept to Session With Carer) produced positive evaluations by both carers and students [3]. In a report on the outcome of a group session following a lecture on dementia that saw carers of people with dementia acting as facilitators whereby participants of the group session were other carers and undergraduate medical students, the students rated the session highly on measures of clarity, interest and relevance [3].

Apart from benefiting the recipients, carers and users also benefit from involvement in teaching in various ways:

- Allows people to learn more about themselves
- Provides personal satisfaction
- Empowers the individual
- Increases confidence
- Enables them to earn money
- Provides a positive use for people's illness
- Acknowledges their expertise
- Improves their understanding of mental and social service staff

- Offers an opportunity to help future patients

The realization that they have something to contribute to training might in itself be therapeutic for carers [3]. It has also been proposed that future undergraduate and postgraduate medical education emphasise skills that foster collaborative partnerships between people with depressive illness, their carers and healthcare providers [9]. This highlights the significance of carers yet again.

There are limitations in the assessment of the outcome of the Session With Carer. The number of students' reflective writings that were reviewed was slightly over 50% of the total number of students for the academic year 2008/2009. Thus the outcome may not be representative of the views of the whole Year 4 student population for that academic year. Nevertheless, this being an outcome report of sorts, a fairly good idea can already be gained of the function and relevance of carers as teachers. The students' reflections and the author's categorization of the points learnt are subjective. Perhaps in future a more objective analysis can be applied. As with patients, carers too are not standardized. Some may offer more information than others and this can affect what the students pick up during the session. In a similar vein, students in the later batches may have gained more insight on the carers' experiences as the carers became more comfortable sharing their experiences, thoughts and feelings. The determination of significant findings is loose. The author decided on the bigger numbers as the determinant.

Conclusion

The findings show that the Session With Carer is very educational, and helps create more awareness of the importance of the carer's role in patient management and support. In other words, carers can act as teachers in creating more public awareness about mental illness and ultimately, help in gradually removing the stigma associated with mental illness. Therefore, carers should be utilized for this purpose.

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