People caring for those with a serious mental illness miss out on support from health services; a programme addressed this need successfully through tailored workshops

Supporting mental health carers' role in recovery

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Abstract Craddock E (2013) Supporting mental health carers' role in recovery. *Nursing Times;* 109: 47, 22-24.
Literature on the care offered by mental health services suggests carer involvement is minimal. This programme aimed to involve carers more by supporting and preparing them to be informed partners, enhancing their contribution to the healing environment and supporting them in tackling stigma. We offered 15 carers access to supportive and educational workshops. Around half, a core group, attended all eight workshops.

Outcome measures showed no significant shifts of thinking or change for the carers. However, contributory factors found during evaluation of the project may explain these findings.

The workshops helped carers to develop resilience and learn to care for themselves and the service users. Peer support developed throughout the programme.

Carers play a crucial role in the healing process within the home and are instrumental in enhancing recovery. However, evidence suggests mental health carers miss out on the relationship that should exist between service providers, service users and carers, which is highlighted in the *Triangle of Care* report (Worthington et al, 2013). Despite good practice directives from the Department of Health (2010) and the National Institute for Health and Clinical Excellence (2009) emphasising the benefits of carers being involved and included, 74% of the 1,000,000 UK mental health carers in the report feel at "breaking point" (Carers UK, 2008).

Carers from black and minority ethnic groups feel particularly unprepared for their caring responsibilities and lack professional support (Sandhu, 2008). The fear of "madness" among BME people adds to the burdens of dealing with diagnosis, disabling symptoms and the complex health system. BME carers' experience is worsened by cultural barriers, poor carer health and social exclusion (Carers UK, 2011).

A project was set up to improve the support offered to carers of people with serious mental illness through group workshops.

A serious mental illness is usually a long-term condition of a remitting and relapsing nature that requires service users and their families and carers to develop life-long coping strategies. All the carers recruited to this project had relatives who had a serious mental illness that met this definition.

Aims of the programme

The project had two main aims: to empower carers by enhancing their understanding of service systems and care interventions; and to develop a model of carer mentoring and peer support.

Method

We addressed data protection, consent and confidentiality before starting the project.

Carers were recruited by being invited to a taster session at the family and carers event held at the trust and through flyers sent to various teams and services.

We intended to recruit 12-15 members, a good group size that would not be too large to overwhelm members or so small that the carers felt in the spotlight (Proctor, 2000). Fifteen were recruited but some

5 key points

1 Carers play a crucial role in recovery from mental health problems

2 Carers of those with serious mental illnesses often miss out on support from health services

3 There is a need to provide support, skills, education and information and coping strategies to all carers

4 Carers' groups can help participants to develop trust and encourage peer support

5 Carers value the opportunity to listen and learn from each other, regardless of how experienced they are as a carer

TABLE 1. **CORE GROUP CHARACTERISTICS**	
Ethnicity	BME: 60%; white: 40%
Gender	Female: 60%; male: 40%
Age	36-55yrs: 60%; 56-75yrs: 40%

dropped out leaving a core group of 10.

The diverse ethnicity of the participants reflected the trust's inpatient profile (Table 1). The carers were predominantly women and aged 36-75 years, similar to patterns noted by others (Carers UK, 2008).

The taster sessions held before the workshops showed carers wanted to gain information and develop skills and strategies rather than hear carers' stories. Although there is value to hearing about other carers' experiences, it is possible that participants were all at a stage where they were looking for practical support and information.

We decided not to allow anyone new to join the group after the third session because we did not want to lose the advantages of a closed group, which allows members to:
» Work within their own ground rules and develop trust;
» Define the boundaries and expectations from staff and each other;
» Offer different perspectives and opportunities to challenge and ask questions – an approach that helps carers rehearse strategies for when dealing with health professionals;
» Take risks in a safe environment;
» Reflect and talk about themselves, as opposed to talking about loved ones.

Eight workshops were facilitated between November 2010 and June 2011

(Table 2). Each lasted two hours and included:
» Topics that the carers requested;
» Expert speakers to present and discuss specified or negotiated issues;
» A community psychiatric nurse to support the project facilitator.

Workshop structure

From the 15 carers recruited, five left due to personal circumstances, leaving a core group of 10. Each workshop was normally attended by five or six.

At the start of the first workshop, the carers agreed ground rules, identified needs and expectations and completed the pre-workshop questionnaire. They were asked about the type of issues they wanted to include in the schedule, a strategy that ensured they were involved and shared ownership of the workshops. Suggestions that overlapped with the trust's family and carer events were not included to avoid covering the same subjects twice.

At the start of each workshop, carers were reminded of the ground rules. As there was a different expert facilitator for each workshop, introductions were always made. Everyone, including the facilitators, wore a name label. A short presentation was followed by time for the carers to ask questions and share information. The second part of the session was for the

carers to consider how the workshop applied to their own experience.

In June 2011, a recall workshop was hosted for the carers and facilitators to reflect on the programme and end with a celebratory lunch.

Results

The results came from the questionnaires, workshop evaluations and reflections from all involved. Table 3 shows some themes that emerged from the workshops.

Discussion

A recall workshop was designed to celebrate the end of phase one of the project. All participants, facilitators and contributing guest experts attended.

One facilitator was pleased to see the carers chatting and laughing together; she felt this was cathartic and symbolic of what they had achieved. Although the carers had been looking for information, they acknowledged learning from each other, highlighting the benefits of peer support (Repper and Carter, 2010). These 10 carers were experienced; many had been caring for five years or longer, yet they still valued being together and listening to each other. From their perspective, the project was a success and they consistently awarded it "excellent" in questionnaire scores. During the workshops, the carers responded

TABLE 2. **FRAMEWORK OF WORKSHOPS**

Workshop topic/theme	Facilitator	Summary of content
1. Introduction	Project facilitator	● Welcome and introduction ● Developing and agreeing ground rules ● Clarifying confidentiality ● Distribution of support and information packs ● Identifying needs and expectations of carers
2. Identity	Service user consultant	● Exploration of personal identity ● Impact of mental illness ● Issues of stigma and discrimination ● Naming the carer group – name chosen from suggestions from the group
3. Boundaries	BME service lead	● The need for boundaries ● Skills practice of saying "no" ● Coping strategies
4. Recovery care approach	Learning and development adviser	● What recovery means for the service user and how carers can contribute
5. Conversation with a psychiatrist	Consultant psychiatrist	● Open discussion – information-giving and opportunity to ask questions
6. Carer perspective	Carer	● A personal perspective and coping strategies ● Forward planning, i.e. the future – what is going to happen when the carer is not there any more?
7. Power	Service user consultant	● The dynamics of power and how carers can claim aspects of power for themselves and use it constructively
8. Peer support	Peer support lead	● What peer support means and how it can work
End and celebration	Project facilitator	● Review of our journey together and consideration of next steps

TABLE 3. THEMES FROM WORKSHOPS

Themes	Carer feelings, experience, thoughts	Group reflections
Not being listened to by health professionals	Confusion that condition was not diagnosed or identified. Staff perceiving behaviour as deviant rather than symptoms of mental illness so delay in receiving treatment and care	Carers acknowledge their feelings and experience. They are the experts and the passage of time proved the carers right
Emotions	A recurring theme, sadness at loss and guilt, for example: "I live in a lovely home but my son doesn't"	● Emotions are normal and part of the process. Important to find allies who will listen – this points to the need for peer support ● To counter emotional responses, there is a need for relevant information and health promotion literature ● Develop a personal resource file of what is there for the carer and service user ● Do not blame self or others ● Update carers on current literature regarding causes of mental illness
Things not going well – recognising deterioration and crisis points	Hospitalisation, exacerbation of illness	● Carers knowing own limitations ● Letting go, allowing professionals to take over support and looking at how carer is looking after self
Stigma and discrimination	Labelling of condition, how society saw the relative and the carer	Accepting and modelling behaviour to relative. Some carers found the use of terms such as psychological distress or even neurological dysfunction more acceptable in managing how other people referred to their loved ones
Culture	Family orientation, having to look after relatives, cultural norms	● These cultural norms were affirmed ● The model of showing that the family cared
Values and beliefs	Carers spoke of their religious faith in seeing them through the rough patches	Helped carers to see how they are aided in their caring role by their values and beliefs

warmly to the facilitators; for example, after the sixth workshop some participants hugged the facilitator – a carer herself. This showed the connection they felt with each other, empathy and shared experiences.

A number of outcomes were identified from the evaluation of this first phase:
» Following a discussion on a topic, one carer felt confident enough to address a matter with her husband's doctor. This was a marked change as she had previously felt marginalised and unable to take action;
» Two carers showed their increased confidence and skills as expert carers by successfully applying to serve on the trust committee for nursing awards;
» By providing the facilitators themselves with supervision, we ensured the project remained embedded in practice and carer-focused.

Evaluation
The project has had positive outcomes for the group in terms of enhancing their carer role, working in with health professionals and empowering their advocacy role.

The workshop evaluations were consistently "excellent" but the questionnaires did not show significant shifts of thinking and change for the carers. This

outcome may be associated with:
» The group were experienced carers;
» The questionnaire design being too simplistic to capture the changes;
» The timing of the questionnaire at the end of workshop eight meant there was a limited time for it to be completed. Perhaps delaying it for three months may have been more appropriate.

Next steps
Another series of workshops started in March 2012. From these, carers will then be recruited to train to become peer supporters. As the trust is already involved in family and carer events, peer supporters can be included in the programme to take a lead in carer support and education.

Conclusion
This phase of the project is just the first of a much larger project. The carers' experiences show there is a need to provide support, skills, education and information and coping strategies to carers.

Carers said this tailored approach that gives them time to be part of a group and access to information was a success. Initiatives to provide support and education to carers require vision, leadership and an investment of resources. While the

findings from this group were specific to them, participant evaluations and facilitators' insights suggest the findings would apply to a wider selection of carers. **NT**

● This article is an abridged version of the Mary Seacole leadership award (2010) report, *Enhancing the Mental Health Carers' Contribution to Healing*. See tinyurl. com/msla-carers

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