Exploring the meaning of recovery for carers: Implications for social work practice

Dr. Joanna Fox, Faculty of Health, Social Care and Education, Anglia Ruskin University, East Road, Cambridge, CB1 1PT, UK

Professor Shula Ramon, University of Hertfordshire, School of Health and Social Work, Room 347 1F300, The Wright Building, College Lane, Hatfield, Herts AL10 9AB, UK

Dr. Nicola Morant, Division of Psychiatry, UCL, Maple House, 149 Tottenham Court Road, London W1T 7NF

Corresponding address

Dr. Joanna Fox, Senior Lecturer, Education and Social Care, Faculty of Health, Social Care and Education, Anglia Ruskin University, East Road, Cambridge,

CB1 1PT, UK

Email: [joanna.fox@anglia.ac.uk](mailto:joanna.fox@anglia.ac.uk)

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Abstract

This paper describes the impact that learning about recovery has on mental health carers, exploring the implications of this research for UK social work and beyond. A steering group co-produced a training intervention on recovery that was delivered by the first author and a carer, both with experiences of recovery, to eleven carers. Mainly qualitative data, with supplementary socio-demographic data, were collected to evaluate the impact of this training. Thematic analysis was applied to the data. Findings suggest that being more ‘recovery-aware’ gives carers increased hope and optimism for the future. Awareness of the impact of caring upon the service user’s life helps carers to promote recovery in their relative, and gain confidence in their own expertise-by-caring. Professional care is fundamental to recovery but needs to build on a partnership model. The carers evaluated the training as helpful, and valued its authenticity in being led by trainers with experience of recovery. Carers’ expectations of professional practice are highlighted, with different approaches discussed that support effective carer involvement in their relative’s care. Recognition of carers’ expertise-by-caring demands a new approach to mental health care, with significant implications for British social work practice.

**Keywords**: Social Work, Mental health, recovery, carers, schizophrenia, qualitative research.

Introduction

The recovery approach posits that people with schizophrenia can lead meaningful lives, beyond the limitation of their mental ill-health (Repper and Perkins,2003). Although central to mental health, with a focus on social inclusion, social workers’ contribution to the recovery model in the UK is under-reported (Tew et al,2012), despite it being a key concept underpinning policy and practice (DH,2011).

UK social work interventions in mental health draw on the unique role of the Approved Mental Health Professional (AMHP) in undertaking mental health assessments and their historical relationship with carers in this process (Rapaport,2005), alongside their role in developing the social model of mental health (Tew,2011). This paper describes the development, delivery and evaluation of an intervention undertaken by a social worker focusing on the role of carers in recovery in the UK. It emphasises social work as strengths-based (Fukai et al,2012), highlighting the experiential wisdom of users and carers at the centre of practice (Ramon,2003).

This approach, promoted in the intervention, changes the relationships between carers and service users as it enables carers to believe in their relative’s potential to lead an autonomous and independent life and redefines relationships between carers and professionals. It makes a useful contribution to recovery-focused social work practice.

The context of recovery

Researchers (Huber et al,1975; Warner,1985; Harding et al, 1987) have posited the recovery model in mental health since the late 1960s. Two traditions have emerged (Slade,2009): clinical recovery which reflects the idea of remission, focusing on reduction of symptoms to enable optimum functioning; and personal recovery which emphasises the importance of achieving a more stable state of well-being to enable full participation in mainstream community.

Personal recovery has been strongly advocated by the service user movement, first in the USA, and now in New Zealand, Australia and the UK (Ramon, Healy, and Renouf,2007). Davidson (2005) noted that the shift in practice to recovery-oriented services in the USA must be strengths-based and individually focused, both supporting the person to manage their condition and to regain a meaningful and constructive membership of the community. New Zealand has promoted services that support recovery by optimising choice and autonomy that enable users to lead valued lives (Lapsley et al,2002).

Tew et al (2012) suggest that UK social work practice, with its commitment to social justice and individual empowerment, needs to both engage in individual practice with users to overcome experiences of social exclusion and to work collectively with communities to promote social inclusion. Additionally, the importance of peer support has been increasingly recognised in the delivery of recovery-oriented services (Repper and Carter,2010) as new roles were created in the UK with the development of Support Time and Recovery Workers (DH,2007) - service users with their own experiences of recovery who are employed to mentor their peers in their recovery journeys. Nevertheless, concerns have been raised that recovery will become the latest buzzword and will simply be a new name for the same old practice (Slade and Hayward,2007).

The views of carers about recovery have hardly been addressed, despite their important role in recovery (SRN,2009); therefore this research seeks to address this gap.

Carers in the UK mental health system

DH (2008) identifies that there were 1.5 million carers of people with serious mental ill-health in 2008.This includes only those designated as the main carers, excluding secondary carers, such as the other parent, siblings, or children. Many care for more than 50 hours per week (DH,2008), making considerable savings in public expenditure (House of Commons Work and Pensions Committee,2008).

Research has illustrated the considerable cost to carers’ physical and psychological health due to the impact of this type of caring (Hogman and Pearson,1995). Caring for someone with mental ill-health is complex and difficulties include:

* Communicating effectively with the person with mental ill-health (Hogman and Pearson,1995).
* Being unsure of how to behave in the carer’s role (Repper et al.,2008).
* Loss of earnings through having to leave work to care (Repper et al,2008).
* ‘Courtesy stigma’ which often results in social isolation (Goffman,1963).
* Experiences of guilt, shame, and grief (Kilyon and Smith,2009) as many carers still give credence to research which conceptualised family systems as contributing to the development of schizophrenia (Laing,1969).

Carers’ relationships with professionals are often complex, because of the conflicting areas of interest and the service user’s right to keep information confidential (Hogman and Pearson,1995).

Policy and Legislation

UK policy recognises the importance of carers and their rights to be included in what happens to their relative, as reflected in the Nearest Relative (NR) status in the Mental Health Act since 1959 (HM Govt,1959). This gives carers the right to request an assessment of their family member who is unwell and to oppose compulsory admission in specific circumstances (HM Govt,1983); although AMHPs can also apply for an assessment and to overrule carers’ wishes since 2007 (HM Govt,2007). Carers have the right to be present in care-planning and at reviewing of the Care Programme Approach; however, their relative’s rights to keep information confidential take priority over carers’ wishes.

The Carers’ Act (1995) gave carers the right to ask for an assessment of their own needs, but not the right for implementation of services to meet identified needs. All carers have the right to a carer’s allowance if they care for a substantial number of hours. Several voluntary organisations provide support groups and advisory services for carers (Rethink,2014), but few organisations have resources to provide respite services.

Social workers engage with carers in a variety of ways. Being the majority discipline among AMHPs they meet carers at crisis point, and their role is to inform carers of their NR responsibilities, as well as to co-ordinate the assessment process for compulsory admission. Although carers may contact social workers outside of their AMPH role, few service users have a mental health social worker allocated to them and their families. This stands in contrast to the traditional focus in social work on working with families, and specifically with mental health carers (Rapaport,2005).

UK social work

UK social workers have been committed to deinstitutionalisation and the resettlement of service users in the community since the 1960s (Ramon,1998), and to the new meaning of recovery since the 1990s (Tew et al,2012). Additionally social work developed the strengths approach, which focuses on identifying and developing strengths in service users, prior to any other discipline (Fukai et al,2012). UK social work educators and researchers were also the first to involve mental health service users as trainers and co-researchers (Ramon, Warrener, and Beresford, 2004). Although most UK mental health social workers prefer a recovery oriented approach, the focus on risk avoidance in their work, especially their AMHP work, and the lack of emphasis on positive and calculated risk-taking in UK mental health services as a whole, mean that all too often recovery and strength-building principles are put aside (Ramon, 2005).

This background highlights current British social work as strengths-focused and recovery-oriented in principle, placing value on experiential wisdom, with a traditionally unique focus on family carers. Carers are however a neglected stakeholder in mental health; we therefore lack research to explore the impact of recovery on their lives and caring behaviour (SRN,2009). This paper draws on these themes and describes research exploring the relevance of the new meaning of recovery to carers; although in order to reflect the primary remit of this special edition, the findings that are presented focus on the specific implications for social work. The following research questions are addressed:

* How do carers define recovery?
* What do carers see as the major obstacles to and opportunities in recovery?
* Do they evaluate the training package as helpful to explore these issues?

Methodology

The project was based on an interpretative paradigm with a qualitative design. Research was exploratory and focused on the collection of rich, in-depth data from small numbers of participants. The first author’s own identity as an expert-by-experience with a diagnosis of schizophrenia and the second trainer’s experience as a carer, were central to the project and informed the research process and the development, delivery and evaluation of the training programme. This personal positioning was made explicit to all participants from the outset.

In order to ensure that the research built on the expertise of other relevant stakeholders, asteering group was established at the project beginning. Steering group members were recruited via local contacts. The group had 7 members: the first author, an additional user-trainer, a carer, a member of a local mental health support charity, two community psychiatric nurses working in the local mental health trust, one with senior management responsibilities, and the trust’s user and carer involvement officer. The steering group met regularly and participated in the design of the training and data collection tools, and contributed in a limited way to data analysis and dissemination.

Design and delivery of training programme

The training programme was designed to focus on personal, practical and policy aspects of recovery. Participants were introduced to recovery, and invited to consider how a service user’s recovery journey might relate to the carer’s journey, and what recovery might mean in practice. Training covered how service users might develop their own well-being strategies, and introduced the WRAP tool (Wellness Recovery Action Planning; Copeland,1997). Service-related issues were also covered (carers’ rights, their involvement in care planning, and the development of direct payments).

Recruitment

The project planned to purposely sample carers, using maximal variation sampling (Flick,2006) to recruit an optimum number of 13-15 participants from diverse backgrounds and caring situations. Recruitment strategies were implemented to access carers from lower socio-economic and hard-to-reach groups. The project was advertised via local contacts in statutory mental health services (early intervention and community services) and voluntary sector services, and via other carer and research networks with the help of steering group members.

In the event, difficulties with recruitment meant that no sampling was necessary, and all eleven carers who expressed an interest in the programme subsequently participated. Potential carer participants were interviewed by the first author in order to ensure informed consent and suitability for the group-based nature of the training, and to introduce the ground rules.

Delivery

The training was delivered to a group of eleven carers in five 2 ½ hour sessions from April to July 2009, with data collection completed in February 2010. All sessions were facilitated by the first author, (a user-trainer), and a carer. It was hoped that the two facilitators would model successful recovery from mental illness and positive carer experiences. Sessions were held in the evenings in a university, and used a range of interactive learning techniques including paired work, formal teaching sessions and group discussions, supported by handouts. There was time in the sessions to discuss reactions to the new knowledge and how it affected participants’ attitudes to caring. Practitioners were invited to speak to the group in two sessions. All training sessions were audio–recorded. Refreshments were provided and the participants’ travel expenses were reimbursed.

Evaluation

Mainly qualitative data were collected to evaluate experiences of participating in the training, its impact on participants’ caring roles and their understanding of recovery. Group and individual-based data were collected before and after the training. Basic socio-demographic data about the carers’ and the service users’ living situations were also collected. The steering group contributed to the design of all data collection tools.

Data collection

**Pre-training programme data collection:** Data were collected to explore what carers already knew about recovery, and what they hoped to gain from participating in the study. A vignette of a hypothetical person with schizophrenia and their carer was used to generate individual written responses about the nature of caring and recovery (Hughes and Huby,2004). These responses were then discussed in a focus group facilitated by the first author, allowing exploration of how views of recovery were shared, compared and collectively constructed in comparison to more private individual-based data (Morgan,1998).

**Post training data collection:** The same vignette used in pre-training data collection was applied as a prompt to generate individual written responses and focus group discussion. In order to encourage open discussion about the training, the focus group was facilitated by two members of the steering group who had been involved in the development, but not the delivery of the training. The focus group evaluated the content and usefulness of the training, how the participants’ awareness of recovery changed and whether it had affected their caring relationships.

**Follow-up data collection:** Semi-structured telephone interviews were conducted by the first author, one month and six months after the end of the training. Questions focused on participants’ understandings of recovery, how this related to both their caring role and their relationships with professionals and services, and whether previously-identified changes in the carers’ attitudes and behaviour were sustained.

All data sources were collected from all eleven participants, with the exception of the pre-training focus group which three carers were unable to attend. The interviews and the focus groups were audio-recorded and transcribed, with any identifying information removed. The study was positively reviewed by Anglia Ruskin University Faculty of Health and Social Care research ethics committee, and informed consent was obtained from all participants. The study was completed in December 2013 as it was undertaken by a sole researcher for a PhD.

Data analysis

Data were analysed using thematic analysis (Braun and Clarke,2006) within NVivo and MS-Word. This enabled an iterative approach of moving between data and broad thematic areas. Data sets associated with each contact point were then explored in more detail in order to develop sub-themes. Analysis was also comparative across the multiple data sources. An inductive approach was adopted in which reflexivity was central to the analytic process (Minkler and Wallerstein,2008), allowing consideration of influences on the development of the themes. Other strategies to enhance validity were deviant case analysis, constant comparison, and discussion of emergent findings between the co-authors, and with carer participants and the members of the steering group. The carers’ perspective proved valuable in providing novel insights into how the data was interpreted (MHRN,2012).

**Findings**

Participant characteristics

The sample of eleven carers was composed of seven women (identified as F) and four men (identified as M). Participants’ characteristics and information about their relatives are presented in Table 1. All participants were White-British apart from F04 who was White-Irish. The female carers’ ages ranged from 51-years-old to 77-years-old and the male carers’ ages ranged from 64-years-old to 78-years-old. Two sets of married couples (M04 and F07; M02 and F03) attended who both supported an adult child with schizophrenia. All except for one carer supported an adult child with schizophrenia; F04 supported her brother who lived in another UK area.

Qualitative findings

The carers’ reactions to recovery are presented with a discussion of how they changed through their participation in the training programme, and how this impacted on their practical caring roles. Findings from all data points are presented to show the development of the respondents’ views over time.

The pre-training point

At the pre-training point, many members of the group described recovery in simple terms, defining a state of ‘being recovered’ as achieving clinical recovery. When asked what recovery meant for her son, F06 wrote down individually:

Hopefully return to normal social interactions and ability to function on a day to day basis; i.e. cooking, personal care and ability to relate to others again without being totally wrapped in self.

The notion of a social recovery with the service user having friendships and leading a life that was valued was similarly not credible to any of the other participants.

Most expressed a sense of grief at the missed opportunities in the lives of their family members, and gave little credence to the possibility of recovery. F01 believed that her son could never have a worthwhile identity with a diagnosis of schizophrenia because

even if they do come through, that they may never be the person that they were before, and I think this is one of the sad things about it that you find it difficult to accept ….

F01 despaired of her son’s situation, and it appeared that he too seemed overcome by learned hopelessness and intransigence as they both mourned the loss of friendships, hobbies and purpose in his life. This distress was similarly experienced by F05 as she considered her daughter’s isolation:

... that is the pain you felt when your child was little and wasn’t invited to a birthday party... but when they’re adults and they still have no friends, you feel it so, so painfully.

Ostracism affected service users and carers alike and was influenced by hidden and overt stigma. Stigmatisation is a barrier to recovery and reduces the choices and friendships of people with schizophrenia and their carers, as carers experience the ‘courtesy stigma’ (Goffman, 1963) of schizophrenia. F05 reflected on this and reported that she believed that the caring identity was of little value and felt a sense of guilt about daughter’s diagnosis:

The really difficult thing in the early stages, well for a long time, is feeling that you are being judged as a carer... it is your fault that your daughter is like that. And there must be something that you have done or something that has made her like this.

Changes following the training

As the training progressed, the carers began to see recovery as a much more complex notion. They hoped that the service user could live a good life despite their mental ill-health, but simultaneously feared that they might relapse. F05 reflects on her daughter’s wish to apply for a job as a chamber maid, which she felt she had to discourage because she felt she had to protect her from failure:

And we’re on that whole rollercoaster again, and I’m trying to protect her from it, but equally I’m feeling awful because I’m stamping her down...

F05 began to realise that recovery was possible and that her daughter could lead a “fulfilling life” as F05, herself, became “more accepting of the limitations of schizophrenia”.

Being more ‘recovery-aware’ gave carers increased hope and optimism for their own and the service user’s future. At the follow-up focus group immediately after the training programme, F02 wrote down the best things about recovery:

It gives you hope. Knowledge of recovery and the illness with all its ups and downs gives you confidence to tackle the difficult as well as the easier decisions.

Learning about recovery had implications for the practicalities of caring. At the programme beginning the carers believed that their caring role was ‘being there and doing for’. They often over-cared for the service user, creating a relationship of dependency as their relative lost confidence in their own ability to live independently. For example, at the pre-training point, as was common to all the female carers, F02 washed her son’s clothes, cleaned his flat and involved him in her family unit more than a typical adult child. She reported her reactions to his stress when he cooked for her:

F02: He has to follow a recipe absolutely exactly and after he had ... been cooking that it had actually been very stressful for him because he had he was just crashing out in the evenings he was just so shattered in the evenings...

F04: It was good that it stretched him a wee bit.

F02: Yes it was. And he is going to continue doing some of it. He doesn’t need to cook all the time…

The carers experienced a dichotomy: wanting to make sure the family member was supported but knowing that they had to develop their own independence.

Learning about recovery dramatically changes the traditional notions of how care is provided from ‘doing for’ to ‘enabling’. Building on positive caring helped the carers to see the difference between ‘mothering’ and ‘smothering’ (as F01 described it). As they moved towards a model of ‘enabling’, rather than ‘doing for’, they began to recognise the need for the user to become independent. This was evidenced at the six-month follow-up when M03 wrote down that he wanted his son “to exercise some control over his own life. To set his own goals and to take steps to achieve them”. This was a point of transition when M03 had become a recovery mentor.

Following participation in the programme, the group became more hopeful about their own and their relative’s future. At the six-month follow-up interview F04 said the best thing about recovery “is the fact that it empowers the person who is the service user and the person who is the carer, and it brings it all back to you: you are the expert”. This marked the beginning of her own recovery as she began to acknowledge her own expertise.

Relationships with professionals

The findings showed that professionals have a key role to play in recovery and a three-cornered partnership between the carer, professionals and the service user is desirable. However F03 described how her son drew on her support but did not permit information about his care to be shared due to her role in a sectioning procedure many years earlier. F02 highlighted how important it was to know the boundaries that governed information-sharing; she described how she, the practitioner and her son had sat down and “discussed guidelines for confidentiality and guidelines on my part as well as [my son’s], so that I knew what we could say to each other”.

The carer’s assessment process which provides an opportunity to share information was known to most of the group. F02 explained that she had found the carer’s assessment process a positive experience that enabled her to communicate directly with the team about her son’s care:

I found it a very useful experience as you can actually say what you find is difficult and the parts that you find difficult to cope with. And that particular set up that they have, I know that was going back to the actual team who see [service user].

Other carers would have preferred guidance and information about how to care effectively to an assessment of needs that could not be met (F05).

Learning about recovery influenced the carers’ expectations both of professional practice and of their relationships with individual practitioners. They thought that recovery requires a proactive professional to arrange activities for the service user, as F02 reported at the six-month follow-up:

So I think actually to persist with him and to... suggest things to him... And yes I think they need to be a bit more proactive...

Fundamentally they believed that ‘doing’ led to recovery rather than a process of ‘being’. They therefore felt that an effective professional should arrange regular activities for the service user that would help lead to their recovery.

Many had received a negative prognosis for their family member from professionals at the time of first diagnosis – despite hopefulness being a foundation of recovery practice. F04 found that her experiences of being excluded and overwhelmed by the negativity of ‘experts’ were a real barrier to recovery. She wrote down that the impediments to recovery were:

CPNs who don’t want to talk to me or see me as part of the recovery process and who say they are the experts and that my brother will never be ‘well’ again or be in recovery.

As they learned more about recovery, it gave the carers greater knowledge, power and confidence, giving them the language of recovery, as F04 stated at the one-month follow-up interview:

I think the most important aspect is that it says we each individually have the responsibility for ourselves and for how we interact with each other. We don’t have to go to health service professionals to ask if we’re doing the right thing, or help us to do the right thing, because basically it just gives the power back to us.

She began to have faith in her own knowledge and ability as a carer rather than relying completely on the ‘experts’. Moreover the carers expected to be treated with more respect and valued as informed members of their relative’s support team. It changed their attitude to themselves, to professional knowledge, and to experiential wisdom, influencing their interactions with professionals.

Training evaluation

The carers evaluated the training programme as useful in enabling them to explore the implications of recovery for caring. Seeing the reality of recovery represented in the experiences of the first author and a carer, who delivered the programme, gave the carers a sense of hope and optimism. F01 valued this and reported:

I mean it was so inspiring! Certainly your side of it, R1 (first author), and to realise the recovery process is possible and that there is life beyond the onset of the illness... And then of course it was interesting to hear it from R2’s (carer trainer) point of view, because that was us. You were our son or daughter, shall we say, and R2 was us...

The carers found elements of the digression and discussion important, but frustrating when one member dominated the discussion. The opportunity to work in small groups helped to overcome this. The strength of the programme lay in its freedom to give the group space to explore their feelings, and although digression was sometimes frustrating it was also necessary. Strong chairing of the future deliveries of the course would be helpful.

**Discussion**

Implications for UK social work

The carers found social workers’ input to their relative’s recovery to be vague and poorly defined; indeed the carers did not mention social worker intervention in their or their relative’s lives. This finding was reported despite social workers having a leading responsibility in the UK in undertaking carer’s assessments (DH,1999) and until recently having had a monopoly on undertaking Mental Health Act Assessments (HM Govt,1983) particularly significant given the carers’ rights as a Nearest Relative.

The carers had clear ideas of best practice to support recovery-oriented work. Most carers felt undervalued by practitioners and often excluded from their relative’s care, despite policy recognition that carers have ‘an expert knowledge of the condition of the person they are supporting and have a close understanding of that person’s own aspirations and needs’ (DH, 2010,p.10). This position runs counter to previous discourses in the 1970s that blamed the family system for its role in contributing to the development of schizophrenia (Laing,1969). The participants were of an age to have encountered these debates and indeed many experienced a sense of guilt as parents of people with this diagnosis. This underlines the need to emphasise to carers their potential for having a positive impact on their relative’s life.

This research found that in an ideal relationship between the carer and the professional, the carer should understand the limits of professional responsibility and the barriers to sharing information, and acknowledge that the opinions expressed by both them and the professional can differ. This should be underpinned by the recognition that the carer’s expertise is different to that of professionals. This highlights the importance of a three-cornered triangle of care between the professionals, carers and service users (Worthington and Rooney,2009), with careful sharing of information by all parties in an agreed and sensitive manner. Ramsey and Till (2009) emphasise the importance of reinforcing messages of hope about the possibilities of recovery to service users and their families right from the start of professional contact – many carers found this lacking.

Uniquely this intervention seeks to work with carers in a new way, focusing on developing their capacity and skills, and recognising the contribution carers can make to their relative’s recovery; moreover it requires professionals to acknowledge carers as ‘experts-by-caring’. Indeed the professional capacity to respond to this new relationship with service users and carers is a natural place for social work as its roots are based in the strengths-approach agenda (Fukai et al,2012).

Currently few family interventions either in the UK or internationally have been developed which have a recovery foundation. Many focus on pre-recovery frameworks such as family systems research and therapy (Laing,1969), expressed emotion research (Brown et al,1972) and studies of family burden (Grad and Sainsbury,1963). The recovery training developed in this research offered a unique opportunity to empower carers in supporting their relatives, allowing them to re-think their approach to caring.

Internationally, Open Dialogue (Seikkula,2011) implemented in Finnish Lapland provides an interesting example of conceptual and methodological development to mental health practice. This method uses a family-centred approach that focuses on recognising the significance of all members of the service user’s network in their assessment and treatment. This process is used throughout treatment and may last for up to two years with regular meetings of all stakeholders in the group, excellent outcomes have been reported. This has the potential to influence the conceptual and methodological evidence base that supports recovery-focused practice - although current UK practice with its focus on the user’s right to confidentiality and autonomy would require significant change to implement this model.

The study’s strengths and limitations

Qualitative data collection methods were primarily employed to collect in-depth data from carers about their views of recovery, with inductive processes used to analyse the data. The research is exploratory with a small sample which makes it more compatible with qualitative than quantitative data. However, the addition of quantitative measures to assess pre-post changes following the training could be a useful addition in future research. The research acknowledged the identities the stakeholders in the research process (Ramon, 2003) therefore a positivist approach that sought to exclude all researcher bias would have been unsuitable.

Carers’ views about recovery may have been influenced by knowing that the trainers had experienced their own recovery. However personal recovery is an approach that is user-owned and defined (Ramsey and Till,2009), and indeed peer support is a key part of the recovery experience (Repper and Carter,2010); it is therefore appropriate for trainers with expertise-by-experience to deliver training of this nature. Similarly the researchers could have been influenced in their interpretation of the respondents’ viewpoints because of their own experiences of recovery; however the process of reflexivity that explicitly acknowledged the positioning of the researchers sought to overcome this limitation, and moreover the findings presented the participants’ voices themselves.

The sample size and its homogeneity may limit the study’s generalisability. The carers’ expertise and characteristics shaped the research as much as their caring identity. Many of the participants changed their caring approach after participating in the training – was this due to the self-selecting sample, who was motivated to change? The sample was an optimum size to support an exploratory study of the meaning of recovery to carers and highlighted issues that need to be verified in studies with more representative samples with a larger carer population.

The study was not able to recruit carers from BME backgrounds or carers from lower socio-economic backgrounds (as Table 1 demonstrates); additionally the carers were all from an older age group which affects their response to the training. White working class people may have lower educational attainment (Goodman and Gregg,2010) which may impact on their willingness to engage in education-based interventions and research. The content of the training needs to be tailored to cultural requirements and individual needs (Glyn et al,2006). The impact of courtesy stigma (Goffman,1963) may be greater for BME carers, with users more stigmatised and isolated from their communities by their diagnoses (Kalathil,2010), leading to their greater reluctance to engage with services, and perceptions of institutionalised racism (CQC & NMHDU,2011)[[1]](#footnote-1). This combination often means that their voice is unheard and is less represented in research and service development. The research should be replicated with a group of carers specifically from different socio-economic backgrounds, age brackets, and hard-to-reach groups.

Conclusion

The findings of this study suggest that learning about recovery is helpful for carers. This unique research programme has a useful contribution to make, as it emphasises the importance of family-oriented care that focuses on the recovery approach – something that is lacking in current practice (Glyn et al,2006). We have recently developed a partnership with the local Recovery College and Anglia Ruskin University, UK to roll out this programme more widely which has the potential to impact positively on local and regional support to carers.

Although British social work may not be ready for methodological developments such as the Open Dialogue, recognising the centrality of expertise-by-caring in recovery practice requires fundamental changes in individual professionals, social work practice and culture, emphasising the usefulness of this research to developing UK recovery practice.

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Table 1: Demographics of the carers and the service users they cared for

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Carer  (F-female)  (M-Male) | Age | Ethnicity | Marital status | Education | Current employment status | Housing status | Cared-for person | Service user age | When service diagnosed with schizophrenia |
| F01 | 68 | White British | Married | Tertiary level | Retired | Owner-  occupier | Son | 39 | > 5 years |
| F02 | 65 | White British | Married | Tertiary level | Language support teacher | Owner-  occupier | Son | 37 | 3- 5 years |
| F03 | 70 | White British | Married to M02 | Tertiary level | Retired | Owner-  occupier | Son | 34 | > 5 years |
| F04 | 51 | White Irish | Civil partnership | Tertiary level | Volunteer worker | Rented accommodation | Brother | 44 | > 5 years |
| F05 | 57 | White British | Married | Tertiary level | Freelance tutor | Owner-occupier | Daughter | 30 | > 5 years |
| F06 | 56 | White British | Married | Secondary level | Sales manager | Owner-occupier | Son | 31 | > 5 years |
| F07 | 77 | White British | Married to M04 | Tertiary level | Retired- but managing a property portfolio | Owner-occupier | Daughter | 46 | 3- 5 years |
| M01 | 70 | White British | Divorced | Tertiary | Semi-retired and self employed as a consultant | Owner-occupier | Son | 27 | > 5 years |
| M02 | 71 | White British | Married to F03 | Tertiary level | Retired | Owner-occupier | Son | 34 | > 5 years |
| M03 | 64 | White British | Married | Tertiary level | Retired | Owner-occupier | Son | 32 | > 5 years |
| M04 | 78 | White British | Married to F07 | Tertiary level | Retired- but managing a property portfolio | Owner-occupier | Daughter | 46 | 3- 5 years |

1. In the UK relatively large numbers of African-Caribbean men receive a diagnosis of schizophrenia compared to white or other minority ethnic groups. They are more likely than their white counterparts to be coerced into services against their wishes, for example through compulsory admission to hospital, and once in hospital they are more likely to be physically restrained by staff and to receive particularly high doses of powerful medication (CQC and NMHDU, 2011). [↑](#footnote-ref-1)