

Building on the recovery approach: the development of a conceptual model of service design for carers in mental health

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Abstract

Carers' views about their role in recovery are under-researched, and studies investigating their needs are underdeveloped. In this study, participatory action research was used; I was supported by a steering group of eight stakeholders to co-produce a training programme on recovery and data collection methods to explore the meaning of recovery for carers. The programme was delivered by me, an expert-by-experience with a diagnosis of schizophrenia, and a carer of her son with a similar diagnosis, to a group of eleven participants. Mainly qualitative data was collected together with supplementary quantitative socio-demographic data from the participants. Selected findings based on the carers' discussions are presented which focus on how the relationship between carers and professionals can most effectively facilitate service user recovery. Issues of information exchange between carers and professionals and the impact of patient confidentiality are highlighted, the nature of recovery practice is considered, and the participants' need to be regarded as 'experts' is addressed. A conceptual model of service design based on a recovery-oriented 'triangle of care' is presented. The potential implementation of this model in the current UK mental health service context is considered with the need for co-production between all stakeholders to ensure its development.

Keywords: mental health, recovery, carers, service change, service development

Introduction

Family carers of people who experience mental ill-health sometimes identify poor experiences of service provision (Repper *et al.*, 2008) as they report that their roles may be complicated by:

- not receiving information about their relative (Repper *et al.*, 2008);
- not understanding their relative's mental health diagnosis (Kilyon & Smith, 2009);
- not being involved in the care team (Worthington & Rooney, 2009).

Fox (2013) utilised participatory action research (PAR) to explore the meaning of recovery to carers, enabling them to reflect on its relevance to their caring role. This article presents selected findings from that study, which focus on how the relationship between carers and professionals can most effectively facilitate service user recovery. It provides an account of the development of a service model for carers based on the triangle of care (TOC) (Worthington & Rooney, 2009); extending this firmly embedded model by building on recovery. The recovery-directed TOC (triangle of care) indicates that professionals, carers and service users should work together in a relationship of trust, transparency and support based on recovery principles. Further discussion highlights how this model can be implemented in UK by building on co-production between stakeholders.

Background

The 2011 census (ONS, 2013) reported that 5.4 million people in England were providing unpaid care; with over 33% providing 20 or more hours care a week. Moreover, DH (2014) reported census data identifying that the general health of carers deteriorates with increasing hours of care provided. Caring significantly impacts on the ability to work full time (DH, 2014), with this difficulty increasing with the number of hours of care provided. Carers Trust (not dated [nd] a) confirms research completed by Arksey *et al.* (2002) that around 1.5 million may be caring for someone with mental health problems or dementia.

Carers can feel undervalued by mental health services (NHS England, 2014), despite their significant contribution to supporting their relative. Reflecting this consideration, UK mental health policy is now set out with an emphasis placed on the role of the carer in this context. This article then highlights carers' potential role in supporting their relatives' recovery and the barriers they sometimes experience.

The current UK mental health strategy (DH, 2011) promised a focus on public health, early intervention, recovery, and reduction of stigma; with recovery perceived as central to service provision. Despite this pronounced commitment to the implementation of recovery-oriented services, recovery is often held to be difficult to quantify (Slade, 2009). However, Leamy *et al.* (2011) have developed a useful perspective; recovery is perceived as a unique journey which requires connectedness, hope and optimism about the future, the creation of identity, meaning in life and the need for empowerment¹. This perspective confirms the need for respectful and hopeful professional support that promotes empowerment (Stickley & Wright, 2011).

With an emphasis on recovery-oriented practice, DH (2011) clearly states the importance of all professionals working with carers to manage risk for the service user, recommending a whole-family approach to care planning. Moreover, the importance of the caring role is reflected in the significant influence carers have historically held in playing a central role in the mental health assessment process as the nearest relative (NR) which is set out in the Mental Health Act (MHA, 1983). The Approved Mental Health Professional (trained to undertake and coordinate mental health assessments for admission into hospital, as defined by the Act) must involve the NR in the process and seek their agreement when possible. The Care Programme Approach, a care management method in mental health, emphasises the importance of ensuring the involvement of carers 'as partners in care' (DH, 2008); thus recognising their central importance in day-to-day care. Despite this recognition, carers report their under-involvement in decision-making and risk management processes (NHS England, 2014).

Interim policy guidance, *Closing the Gap* (Social Care, Local Government & Care Partnership Directorate, 2014), highlighted the former Conservative/Liberal Democrat Coalition Government's commitment to reduce the gap between the quality and availability of mental and physical healthcare. It reinforced the need to implement the TOC in mental health service provision. The TOC also emphasises the need for better local strategic involvement of carers and families in the care planning and treatment of people with mental ill-health.

The Carers Strategy (DH, 2010), introduced by the previous Coalition Government and due to be updated in 2016 (but not yet completed), recognised that carers have an expert knowledge of the condition of the person they support and often understand that person's own aspirations and needs. It focuses on carers' rights to a life outside caring and their need for personalised support to enable them to enjoy a family and community life, promising to involve them from the outset in both designing local care provision and planning individual care packages. The Care Act (2014) also emphasises carers' needs by acknowledging the role of services in supporting their wellbeing. This Act, building on earlier legislation (DH, 1999), reinforces carers' rights to receive an assessment and confers new rights to receive services.

NHS England (2014, p.14) has committed 'to include carers in work around developing standards and service components for personalised care planning to help ensure carers are integral to the care and support planning process...'. However, despite this raft of policy and legislation emphasising best practice, NHS England (2014) identifies the following needs highlighted by carers of professional support:

¹ This has been given the acronym CHIME; please note the highlighted letter in each word.

- to be recognised as a carer;
- to share information between carers and other professionals;
- to signpost information and link professionals together;
- to ensure that care is flexible and available when required;
- to recognise the needs of carers in both their caring role and in maintaining their own health and wellbeing;
- to recognise them as an expert-in-care;
- to treat them with dignity and compassion.

This reinforces earlier research by Repper *et al.* (2008) and Kilyon & Smith (2009) which reported similar needs faced by carers; reinforcing the need to implement a recovery-oriented TOC.

Despite the emphasis on recovery (DH, 2011), with a commitment to involving carers (DH, 2014; NHS England, 2014), the carers' role in the recovery process is not well understood (Kilyon & Smith, 2009). The wider study undertaken in Fox (2013) sought to address the gap in the literature about meaning of the recovery model to carers and to explore its impact on their caring roles. This article, however, specifically focuses on exploring and examining the elements of a recovery-directed relationship between the carer and the professional as there is limited research on this topic; the corresponding relationships of recovery between the carer and the service user are discussed in more detail in Fox *et al.* (2015), and indeed, the process of recovery-directed relationships between professionals and users is the focus of much research (Stickley & Wright, 2011).

Methodology

This study utilised PAR (participatory action research) (Minkler & Wallerstein, 2008) within an inductive paradigm to explore the meaning of recovery to carers. Winter & Munn-Giddings, (2001, p.5) note it is '... a process which alternates continuously between inquiry and action, between practice and innovative thinking – a developmental spiral of practical decision-making and evaluation reflection'. Reflexivity consists of critically evaluating one's own professional and personal values through the action research cycle to yield improvement in the research and to generate theory. The steering group, representing academic, practice and experiential wisdom (Glasby & Beresford, 2006) co-produced a training programme on recovery and data collection methods to explore the meaning of recovery to carers through the action research cycle. This forms an exploratory study therefore neither the intervention nor the research tools were piloted outside the group.

Ethical approval was gained from Anglia Ruskin University Ethics Committee.

It was difficult to recruit either the ideal sample of carers or to recruit to numbers, an issue reflected in other studies (Rhodes *et al.*, 2002; Tanskanen *et al.*, 2011). Carers can often be overburdened by caring, and the demands of their task can fluctuate, making their lives complicated and busy, therefore committing to training can be practically and emotionally difficult. Consequently, convenience sampling (Flick, 2009) was utilised to recruit eleven carers of people with schizophrenia to the research. Participants were accessed via staff referral (2), information circulated via voluntary local groups such as Rethink (2), information circulated widely across the region by the Mental Health Research Network² to voluntary organisations (6), and presentations at stakeholder groups (1).

² MHRN has now been replaced by the CLAHRC (Collaborative Leadership in Applied Health Research and Care).

The sample, ultimately recruited, consisted of eleven carers, seven women and four men; with two married couples attending (M04³ and F07; M02 and F03). All of the carers supported an older adult child apart from F04 who supported her brother. Ages ranged from 51-78. All were White-British apart from F04, who was White-Irish. The carers were from professional and affluent backgrounds (mainly owner-occupiers of their houses), and were well educated with the majority having completed graduate level training or equivalent; therefore they were not representative of the wider population.

Informed consent from all of the research participants was obtained. A telephone or face-to-face interview was held with each participant prior to their involvement to ensure they understood both the risks and benefits of participation, the nature of their role, and how their data would be used. Each participant was given an information sheet about the research, and asked to provide written consent to confirm that they understood the implications of their involvement.

Training on the recovery approach was delivered to this group to inform them about and explore the meaning of the recovery concept. The training programme consisted of five sessions of three hours delivered fortnightly. It was delivered jointly by me (a service user) and a carer, utilising our personal experiences of expertise-by-experience.

The training programme used material suitable for carers at different stages in their caring journey. It focused initially on enabling them to recognise their own needs as a person, and not just as a carer. Research was highlighted that identified the support that carers stipulate they require in carrying out their caring tasks; enabling them to see that they were not alone in expressing these needs (Banks *et al.*, 1998). The trainers emphasised that service users should own their personal recovery journey, considering this by discussing what the service user might want to achieve from their recovery in contrast to what the carer might want for their relative. This allowed the carers to separate their vision for their relative's recovery from that of the service user. WRAP (Wellness Recovery Action Planning) is a key element of recovery practice as it focuses on a strengths-based approach to care (Rapp & Goscha, 2012); such practices build on the capabilities of the service user rather than focusing on what they cannot achieve. It enables the user to develop their capacity to recognise their symptoms of relapse and to be aware of what promotes their wellbeing; this enables the carers to support the service user to increasingly self-manage their illness. The trainers reinforced the message that carers can learn to care effectively by caring for recovery to become recovery mentors.

Research data were collected on two levels: first on an individual level, and second at a collective group level. Data were collected on the individual level using three methods. To establish a point of comparison, at the first meeting carers were firstly asked to respond in writing to open questions about their knowledge of recovery and how it related to their caring situation; secondly to fill in a questionnaire with open and closed questions to capture socio-demographic data and data about their caring situation; and thirdly to respond in writing to three questions about a vignette. Hughes (1998, p.381) described vignettes as 'stories about individuals and situations, which make reference to important points in the study of perceptions, beliefs and attitudes'. They provide participants with the opportunity to highlight issues 'from a non-personal and therefore less threatening perspective' (*ibid*, p.383). These written questionnaires were presented to carers both before and after the training programme to identify changes in their knowledge and caring behaviour following the intervention.

³ Male carers are identified by 'M' and female carers are identified by 'F'. The participants were immediately anonymised in all written documentation by being given an appropriate letter for their gender followed by a number.

Focus group discussion was used to explore change at a group level. The discussions centred on the original questions and the vignette to which they had responded earlier. Focus groups are particularly useful for eliciting the views as they create 'concentrated conversations' (Morgan, 1998, p.31) through 'a process of sharing and comparing among the participants' (p.12). A focus group was held before the training programme and another focus group was held at the final meeting facilitated by two members of the steering group who had not been involved in delivering the training programme. This enabled the carers to reflect on the training programme honestly but ensured that the facilitators were familiar with its content.

Telephone interviews were used for the follow up contact at one and six months to enable carers to report any sustained changes following the training period. The telephone interviews were semi-structured, comprising mainly open questions. The themes that emerged were further triangulated with data from the focus groups and written responses.

The whole content of the training sessions, focus groups and semi-structured interviews were audio-taped, with consent. The data were anonymised immediately during transcription with all identifying information removed. Thematic data analysis (Braun & Clarke, 2006) was applied to the qualitative data. Braun & Clarke *op cit.* contend that themes do not merely emerge from the data corpus during the process of analysis but are rather discovered by a researcher engaging in an active process of analysis. I initially used NVivo to manage the whole dataset and break down the mass of information and Word to allow me to work with and transform the data by typing my ideas as they emerged from the quotations. I moved constantly between the two to ensure the analysis was grounded in the data using inductive techniques to generate the general themes of the project. The themes were fed back to the carers and steering group for validation and were agreed as appropriate.

Findings

The findings focus on exploring how the relationship between carers and professionals can most effectively facilitate recovery: firstly, by highlighting their experiences of managing issues of patient confidentiality and information exchange with practitioners and service users; secondly, by discussing carers' changing understanding of recovery practice; and, thirdly, by exploring their need to be recognised as 'experts' by professionals. Data is presented covering three periods of time: before the delivery of the training, during the training, and at the follow up points.

Managing patient confidentiality and information exchange to care effectively

A central theme that emerged at all stages of the research was the need for the carers to have sufficient and appropriate information to care effectively for their relative. Before the training M03 noted that information sharing should be based on 'cooperation as part of a team which includes my son, wife, CPN, psychiatrist and any relevant key workers'. He believed this was essential to help him to support his son effectively.

Central to this experience, was the issue of patient confidentiality which was highlighted as a barrier to the support carers provided. During the training programme, F03 explained how she was excluded from information about her son's care at his request; however, she described what she experienced as best practice when her son had been supported by an assertive outreach team:

So they seemed to have a different approach... I could tell his key worker, I could ring her up and tell her something and I was quite happy that it wouldn't be divulged to [son]... I trusted them as well. They were very professional but I could communicate to them without it getting back to [son] and upsetting the situation.

In this research, which focused on carers' views, processes of information sharing and the need to preserve confidentiality were issues of concern that carers believed prevented them from supporting their relative effectively; in spite of this, it would be inappropriate for a professional to share information about their client unless the service user had expressly consented for information to be shared. Moreover, F03 reported how information she divulged during a carer assessment had been shared with her son; she believed information she shared should be similarly confidential to that of the service user.

This important theme punctuated much discussion during the research; it was echoed in relation to debate about carer assessments, which are a systematic way in which services seek to communicate with carers who offer regular and substantial care – and form an important focus for carers' contact with professionals. Participant experiences of this process were mixed, F06 reported:

I enjoyed the chat, I had a bit of a cry, and she didn't know much about schizophrenia but she was a good listener. And I haven't heard from her since.

F02 explained that she had found the carers' assessment process a relatively positive experience that enabled her to communicate directly with the team about her son's care from her point of view, reporting during the training:

I found it a very useful experience as you can actually say what you find is difficult and the parts that you find are 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].

A carer assessment can be a key tool for facilitating communication; however, the participants noted that a carer assessment is less important when there is an effective working relationship with the professional, because information flows between the three parties in such a 'three-cornered partnership' (M03). However, when no such three-cornered partnership exists, carers believed that a carer assessment took on a more important role as a fundamental opportunity for the carer to meet with a professional, ask their own questions and to focus on their own needs, rather than that of the user. This discussion highlights the difficult balance that professionals have to maintain in managing the sometimes conflicting demands between the service user and carer in managing information sharing and confidentiality issues.

Recovery practice

The nature of recovery practice was another central theme that emerged at each stage of the research. Instilling hope is a key part of developing recovery potential (Leamy *et al.*, 2011), yet F07 reported before participation in the training how the lack of hope was the biggest barrier to promoting recovery when working with staff: 'Being told my daughter has no insight and seems to be written off'. This engendered a sense of hopelessness in both her as a carer and in her daughter's use of services. M04, her husband, added to this, noting:

I think if they... lack insight, they are in a very difficult position, but if that patient has insight and can accept that they need to take their medication, that they need to take it for the rest of their lives... then if they are on that path you can have a lot of hope.

The medical model was seen at this stage in the study as the most effective treatment frame to support professional involvement in the service user's care; the carers had little faith in the potential of recovery to develop effective working relationships between carers, users and professionals. Only F04, a carer who had her own experience of mental distress, expressed some concerns with a mental health service dominated by the medical model:

If they sit inside the medical model, like they do in the hospital, you've got a problem like a broken arm, so they are going like you've got the broken head, so take the tablets, and here's how we're going to mend it up...

This influenced her relationship with professionals as she felt they had little focus on the recovery model.

During participation in the training, this theme was developed by consideration of the difficulty of conceptualising how recovery practice might look. The local Early Intervention in Psychosis (EIP) team was invited to a training session and described how they promoted recovery by ensuring practice encompassed 'some positive risk thinking'; they presumed a position of communication with the family as well as the user, unless the user expressly objected. Indeed, reflecting on this support offered by the EIP team, the carers recognised that real recovery practice demands much more of professionals than traditional practice. F05 reported that recovery practice is:

... very much more difficult for them than being a psychiatric social worker who monitors and talks to someone, but a recovery worker [is] doing things like finding work and stuff.

In support of this point, F03 believed occupational therapists were the most successful professionals because they 'actually tackle the person behind the illness and focus on the interest and get them motivated to do things'.

The carers felt that professional support was fundamental to the success of the service user's recovery. M02 emphasised the importance of a professional working as a mentor with the service user:

It's no use doing it as a parent, because we have been in there for years telling them what to do... advising them or something. But somebody else who can get that spark going.

However they assumed that the recovery mentor should be a paid professional rather than a peer with experience of mental ill-health⁴, whereas many service users report having recovered with support from peers despite professional intervention (Coleman, 1999).

Recovery practice encourages the service user to actively engage in meaningful mainstream community activities of their own choosing. Carer participants believed that social inclusion was central to making recovery possible for the service user. F01 reported at the six-month follow up that a CPN had suggested that her son go to a sports day with other mental health service users, and he had replied: 'I like to spend my time with normal people'. The mental health service had missed the fundamental meaning of recovery, which the service user himself clearly expressed. This service encouraged service users to be active in a segregated community of people with a diagnosis of mental ill-health.

At the pre-intervention stage earlier in this section, F07 and M04 expressed the lack of hope they experienced. In contrast, a belief in recovery practice engendered a sense of optimism in the carers. At the one-month follow up M03 reported:

And to hear the early intervention team talk seriously about the recovery model and the idea of recovery is something that is genuine and possible, it's terrific, it's a terrific antidote to the more despairing negative feeling and with that antidote it brings with it optimism, energy to stay with that things can be done, things can change for the better, and with that energy one can do things.

⁴ This mental health trust was expanding its training and employment of peer support workers, experts-by-experience who offered support and recovery guidance to other service users.

Becoming an expert-by-caring

Carers felt that their relationships with professionals should be based on a sense of mutual respect for the others' respective expertise; this was a key theme in the findings. Before the training, F04 reported that this contact should be informed by an understanding that she had expert knowledge about her relative from caring, stating:

Being asked my opinion and respected by the health authority and having a circle of support, professional and personal, who acknowledge me and listen to my concerns.

However, sometimes the feelings that carers experienced presented a barrier to effective working relationships with professionals. F05 felt a sense of guilt that she never did enough to support her daughter; this feeling made her defensive. She needed professionals to acknowledge her distress as she stated the most difficult things were:

Going over the same thing with professionals. Feeling judged by professionals. Feeling helpless in the face of [daughter's] distress.

Following the training programme, the carers reported how their relationship with professionals had changed as they developed a sense of expertise-by-caring. A married couple, F07 and M04, gained more confidence from participation in the programme because they themselves could talk 'in a more knowledgeable way about the illness'. Moreover, F04 felt empowered by learning about recovery, stating 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... because basically it just gives the power back to us.

This section shows the complexity of the carers' relationship with caring and working with professionals. It reveals the new relationship with professionals that not only carers but also service users need in a recovery model; this can only be achieved by effective partnership between all stakeholders.

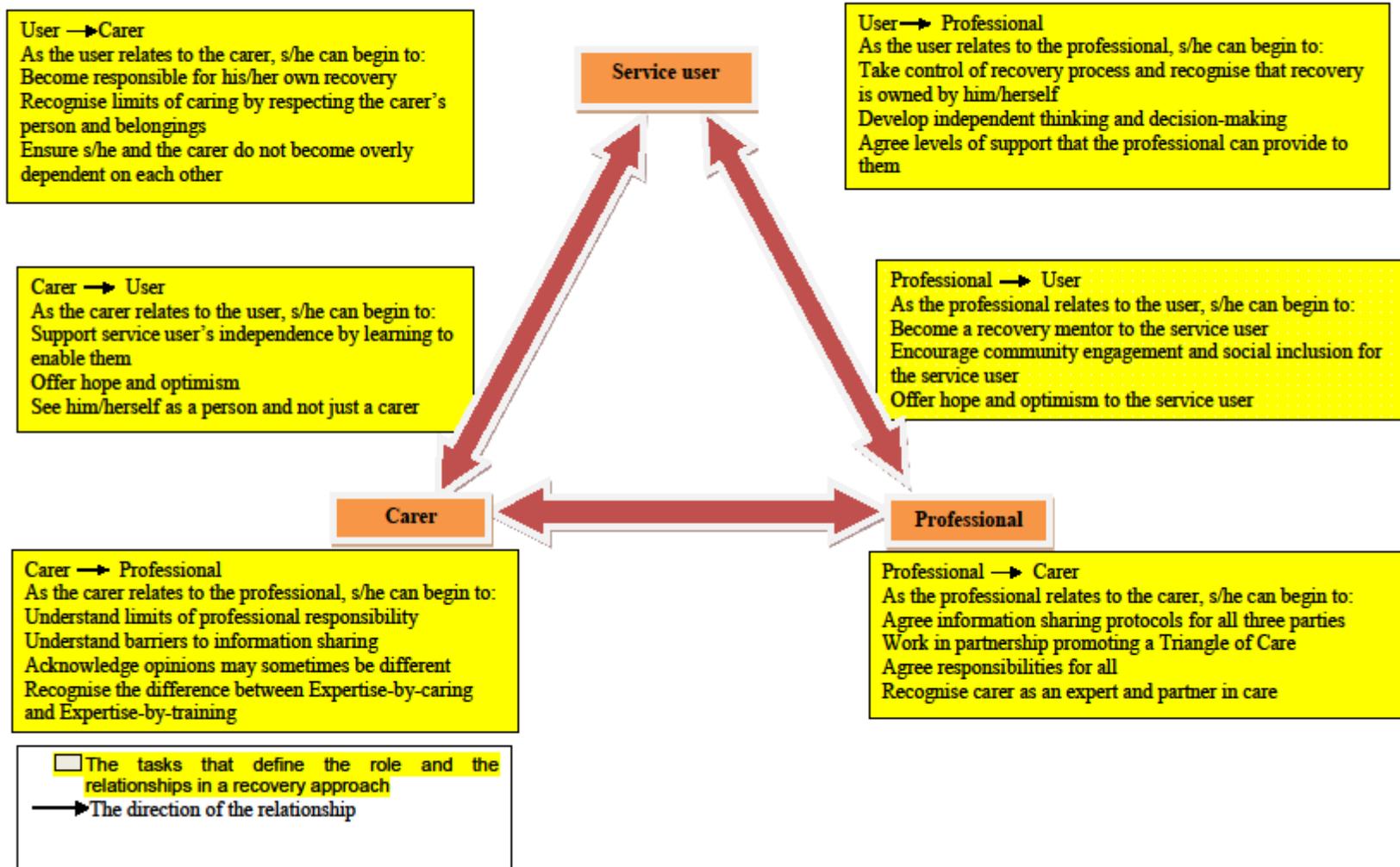
Discussion

Recovery is a service model of increasing influence (DH, 2011); however, despite policy rhetoric, carer involvement in care planning processes and service monitoring is less developed than that of service users. **Figure 1** builds on the TOC (Worthington & Rooney, *op cit.*) by incorporating the study's findings and reflecting research identified in the background. It suggests that carers and professionals can relate in a recovery-directed relationship by:

- understanding the limits of professional responsibility and boundaries;
- agreeing actions and responsibilities;
- recognising the strengths, limits and differences in each of their expertise.

Figure 1 emphasises the importance of both the professional and the carer understanding each other's responsibilities and the boundaries that limit their ability to share information (Kilyon & Smith, 2009). It underlines the need to establish processes for agreeing responsibilities about the support that will be provided, as stated by DH (2011), and by facilitating open and honest debate about what information can be shared (NHS England, 2014). Building on the findings, **Figure 1** suggests that carers and professionals need to recognise the difference between the kinds of knowledge that they both have; by understanding this they can acknowledge their respective expertise and consider how this influences and limits their actions (Fox *et al.*, 2015). It focuses on recovery practice by emphasising a strengths approach to care (Rapp & Goscha, 2012).

Figure 1. A recovery-oriented triangle of care.



The relationship between the stakeholders in **Figure 1** suggests a movement towards systemic practice based on cooperation between the different stakeholders. Increasingly, the importance of systemic practice is becoming recognised in mental health care; one such example is Open Dialogue (Seikkula, 2011), originally developed in Finland, now increasingly used in the UK NHS context. Open Dialogue practitioners use the service user's network, incorporating family, other significant support, and professionals around the service user to empower the service user in crisis and to promote their recovery. It emphasises consistency of professional care, reduced reliance on anti-psychotic medication, increased reliance on the importance of the user's network, and flexibility in approach. This reflects elements of the conceptual model developed in this research, which focus on the primacy of the service user with recognition of the carer's and professionals' potential contribution to recovery processes; underlining the validity of its development.

The TOC has now become (Carers Trust, [nd] b) a quality assurance programme to support mental health providers across England to achieve best practice in carer support. The Carers Trust underlines that guidelines and policies are needed that support overall operational practice rather than just the existence of pockets of good practice by individual teams or staff. This provides momentum to the development of a service model that incorporates the views of carers in a TOC.

Boardman & Shepherd (2012) believe that services need to change on three levels to make recovery a reality in UK: practice with staff and professional training; service organisation and delivery; and the culture of services. Change must happen systematically, accompanied by service user and carer collaboration in the redesign of services. At the level of the relationship between the practitioner and service users there needs to be a shift of emphasis to partnership between experts-by-experience, with professionals facilitating recovery, offering hope and encouraging full inclusion in the community. At the cultural level, service users and carers need to be involved at all levels of decision-making in the organisation regarding staff development, management processes and to be physically present at all levels in the organisation.

Ramon (2011) supports this and emphasises that service change can only be implemented by each organisation becoming a 'learning organisation' (Senge, 1990; Gould & Baldwin, 2004) with a participatory approach to learning in order for transformative change to occur. Service reconfiguration needs to include the views and opinions of all stakeholders at all levels of the system (Ramon, 2011; Boardman & Shepherd, 2012). Implementing Recovery Oriented Change (ImROC, [nd]), an organisation commissioned by the Government to implement recovery across mental health services, echoes this and emphasises the need to ensure involvement at every level to bring about culture change in mental health services.

Strengths and limitations of the research

This article presents selected findings from Fox (2013), which focus on how the relationship between carers and professionals can effectively facilitate recovery. However, this remains an under-researched area with a dearth of literature focused on the needs of carers in mental health recovery (Kilyon & Smith, 2009) and even more widely on research about carers in mental health (MHRN, 2012).

There are some limitations related to the nature of the sample and the generation of this conceptual model based on a TOC. The sample consisted of representatives from the majority ethnic population, who were mainly affluent and well educated, as discussed in the methodology; it was not representative of a wider population. The carers in this study could articulate their needs and wishes, and be assertive about their expectations from professionals; this may impact on the kind of services they are able to access for their relative and the kind of relationship they expect with professionals. They possess a sense of expertise-by-caring (MHRN, 2012), which allows them to develop their confidence when working with professionals. The composition of the sample therefore influenced the development of the conceptual model.

It would be useful to replicate this programme with a more diverse group; and thus further research would enable the model to be confirmed or refuted.

Conclusion

This article has described selected findings which focus on how the relationship between carers and professionals can effectively facilitate recovery. The research was founded on an emancipatory methodology that emphasises action, learning and transformative change (Minkler & Wallerstein, 2008), therefore its application to practical service delivery and implementation is important. A model based on the TOC that represents recovery-directed relationships between carers, service users and professionals was introduced; with a focus on the relationship between carers and professionals. Some limitations were discussed in the way in which it was generated and confirms that further validation is needed by more research.

By teaching carers about recovery, they can begin to participate in the growing debate about the future of mental health services, and as a much neglected stakeholder group (MHRN, 2012), they need an opportunity to participate in shaping its development. Only by ensuring their involvement in service development, alongside that of service users, can sustained and prolonged recovery-directed transformation to mental health services be delivered (ImROC, [nd]).

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Conflict of interest

There is no conflict of interest.

References

- Arksey, H., O'Malley, L., Baldwin, S. & Harris, J. (2002) *Services to Support People with Mental Health Problems. Literature Review Report for the National Coordinating Centre for NHS Delivery and Organisation R&D*, York: SPRU, University of York.
- Banks, P., Cheeseman, C. & Maggs, S. (1998) *The Carers Compass: Directions for Improving Support to Carers*, London: Kings Fund.
- Boardman, J. & Shepherd, G. (2012) 'Developing successful recovery-oriented mental health services', in Ryan, P., Ramon, S. & Greacen, T. (Eds.), *Empowerment, Lifelong Learning and Recovery in Mental Health*, Basingstoke: Palgrave Macmillan, pp. 69-81.
- Braun, V. & Clarke, V. (2006) 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, **3**, pp. 77-101.
- Carers Trust [nd] (a) accessed 01/04/17 at: <https://carers.org/key-facts-about-carers-and-people-they-care>
- Carers Trust [nd] (b) *The Triangle of Care*, accessed 01/05/17 at: <https://professionals.carers.org/working-mental-health-carers/triangle-care-mental-health>
- Coleman, R. (1999) *Recovery: An Alien Concept*, Gloucester: Hansell.
- Department of Health (1999) *A National Framework for Mental Health: Modern Standards and Service Models*, London: HMSO.

Department of Health (2008) *Making the CPA Work for You*, accessed 02/05/17 at: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_083651.pdf

Department of Health (DH) (2010) *Recognised, Valued and Supported: Next Steps for the Carers Strategy*, London: HMSO.

Department of Health (DH) (2011) *No Health Without Mental Health: Delivering Better Mental Health Outcomes for People of all Ages*, London: HMSO.

Department of Health (DH) (2014) *Carers Strategy: Second National Action Plan 2014-2016*, London: Department of Health, accessed 01/04/17 at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/368478/Carers_Strategy_-_Second_National_Action_Plan_2014_-_2016.pdf

Flick, U. (2009) *An Introduction to Qualitative Research*, London: Sage.

Fox, J. (2013) *An Exploration of the Role of Carers in the Recovery of People with Schizophrenia*, (PhD), Cambridge: Anglia Ruskin University.

Fox, J., Ramon, S. & Morant, N. (2015) 'Exploring the meaning of recovery for carers: implications for social work practice', *The British Journal of Social Work*, **42**, pp. 443-460.

Glasby, J. & Beresford, P. (2006) 'Who knows best? Evidence based practice and the service user contribution', *Critical Social Policy*, **26**(1), pp. 268-284.

Gould, N. & Baldwin, M. (Eds.) (2004) *Social Work, Critical Reflection and the Learning Organisation*, Aldershot: Ashgate.

Hughes, R. (1998) 'Considering the vignette technique and its application to a study of drug injecting and HIV risk and safer behaviour', *Sociology of Health and Illness*, **20**(3), pp. 381-400.

HM Government (1983) *Mental Health Act 1983*, London: HMSO.

HM Government (2014) *The Care Act 2014*, London: HMSO.

Implementing Recovery Oriented Change (ImROC) [nd], accessed 10/11/16 at: <http://imroc.org/resources-supporting-the-10-key-challenges/>

Kilyon, J. & Smith, T. (Eds.) (2009) *A Straight Talking Introduction to Caring for Someone with Mental Health Problems*, Ross-on-Wye: PCCS Books Ltd.

Leamy, M., Bird, V., Le Boutillier, C., Williams, J. & Slade, M. (2011) 'Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis', *British Journal of Psychiatry*, **199**(6), pp. 445-452.

Mental Health Research Network (MHRN) (2012) *Good Practice Guidance for Involving Carers, Family Members and Close Friends of Service Users in Research*, London: Mental Health Research Network.

Minkler, M. & Wallerstein, N. (Eds.) (2008) *Community Based Participatory Research for Health: From Process to Outcomes*, San Fransisco: Jossey Bass, Wiley and Sons.

Morgan, D.L. (1998) *The Focus Group Guidebook. Focus Group Kit 1*, Thousand Oaks: Sage.

NHS England (2014) *NHS England's Commitment to Carers*, London: Medical directorate and Nursing directorate, accessed 18/04/17 at: <https://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf>

ONS (2013) *Full Story: The Gender Gap in Unpaid Care Provision: Is there an Impact on Health and Economic Position?*, London: ONS, accessed 18/04/17 at: http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/dcp171776_310295.pdf

Ramon, S. (2011) 'Organisational change in the context of recovery-oriented services', *The Journal of Mental Health Training, Education and Practice*, **6**(1) pp. 37-46.

Rapp, C. & Goscha, R. (2012) *The Strengths Model: A Recovery Oriented Approach to Mental Health Services*, Oxford: Oxford University Press.

Repper, J., Nolan, M., Grant, G. & Curran, M. (2008) *Family Carers on the Margins: Experiences of Assessment in Mental Health. Report to the National Coordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO)*, London: NCCSDO.

Rhodes, P., Nocon, A., Booth, M., Chowdrey, M.Y., Fabian, A., Lambert, N., Mohammed, F. & Walgrove, T. (2002) 'A service users' research advisory group from the perspectives of both service users and researchers', *Health and Social Care in the Community*, **10**(5), pp. 402-409.

Seikkula, J. (2011) 'Becoming dialogical: psychotherapy or a way of life?', *Australian and New Zealand Journal of Family Therapy*, **32**(3), pp. 179-193.

Senge, P. (1990) *The Fifth Discipline: The Art and Practice of Learning Organisations*, New York: Doubleday.

Slade, M. (2009) *Personal Recovery and Mental Illness: A Guide for Mental Health Professionals*, Cambridge: Cambridge University Press.

Social Care, Local Government & Care Partnership Directorate (2014) *Closing the Gap: Priorities for Essential Change in Mental Health*, accessed 18/04/17 at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/281250/Closing_the_gap_V2_-_17_Feb_2014.pdf

Stickley, T. & Wright, N. (2011) 'The British research evidence for recovery, papers published between 2006 and 2009 (inclusive). Part One: a review of the peer reviewed literature using a systematic approach', *Journal of Psychiatric and Mental Health Nursing*, **18**(3), pp. 247-256.

SRN (The Scottish Recovery Network) (2009) *Carers and Supporting Recovery: A Report Commissioned by the Scottish Recovery Network*, Glasgow: SRN.

Tanskanen, S., Morant, N., Hinton, M., Lloyd-Evans, B., Crosby, M., Killaspy, H., Raine, R., Pilling, S. & Johnson, S. (2011) 'Service user and carer experiences of seeking help for a first episode of psychosis: a UK qualitative study', *BMC Psychiatry*, **11**, pp. 157-168.

Winter, R. & Munn-Giddings, C. (2001) *A Handbook for Action Research in Health and Social Care*, London: Routledge.

Worthington, A. & Rooney, P. (2009) *Triangle of Care: Carers Included: A Guide to Best Practice in Acute Mental Health Care*, London: National Mental Health Development Unit and The Princess Royal Trust for Carers.

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