Development of a framework for recovery in older people with mental disorder

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Objective: To evaluate whether a conceptual framework of recovery developed for working age adults holds value for users of older people's mental health services, including those with dementia.

Method: Thirty-eight qualitative interviews were undertaken with service users and carers from an older people's mental health service in South London and were analysed using grounded theory methods.

Results: Components of recovery, which appear to be meaningful to older people with mental disorder include the following: (i) the impact of illness, (ii) the significance of personal responsibility, and (iii) specific coping strategies. Unlike their younger peers, older people did not aspire to a new and revised sense of identity, nor did they seek peer support from others with lived experience of mental illness. Three components of recovery were identified as being distinct to older people: the significance of an established and enduring sense of identity; coping strategies, which provide continuity and reinforce identity; and the associated impact of physical illness. Finally, two additional components of recovery were identified for people with dementia: (i) the changing experience over time and (ii) support from others.

Conclusion: Mental health policy is increasingly framed in terms of 'recovery'. This paper provides empirical evidence of how it applies to users of older people's mental health services. Practice implications include the need to focus on the maintenance of identity, and embed the values of empowerment, agency and self-management within service delivery. Copyright © 2012 John Wiley & Sons, Ltd.

Background

The recovery movement in mental health has developed over the last decade into a dominant paradigm in policy and practice. It has evolved from recognition of the value of the narratives of adults of working age with a lived experience of mental illness, and the movement has sought to redefine expectations and outcomes in mental disorder. Within this new framework for understanding mental illness, recovery is led and instigated by the person with the mental illness, and may or may not involve input from mental health services. The process of recovery typically involves taking back control of one's life and one's illness, and taking personal responsibility for one's own recovery (Roberts and Wolfson, 2004). A decrease in symptoms is not a pre-requisite for recovery. Key components include hope, acceptance, agency, peer support, valued social roles and connectedness (Bellack, 2006; Andresen et al., 2003; Ralph, 2000; Ridgeway, 2001, Davidson et al., 2005). A definitive framework informed by a recent systematic review of available literature on recovery (Leamy et al., 2011) is summarised in Table 1.

Table 1 Key components of recovery (Leamy *et al.*, 2011)

Components of recovery	Recovery processes
Connectedness	Peer support and support groups, relationships, support from others, being part of the community
Hope and optimism about the future	Belief in possibility of recovery, motivation to change, hope inspiring relationships,
Identity	Dimensions of identity, rebuilding/redefining positive sense of identity, overcoming stigma
Meaning in life	Meaning of mental illness experiences, spirituality, quality of life, meaningful life and social roles, rebuilding life
Empowerment	Personal responsibility, control over life, focussing on strengths

The impact of the recovery philosophy upon mental health service policy, delivery and research for working age adults has been substantial across North America, Australia and UK, and is likely to continue to be an important influence. Equivalent developments and research in older people's mental health services have not yet taken place, and the possible implications of a recovery approach are just starting to be explored (Hill *et al.*, 2010; Adams, 2010; Woods, 2007; Martin, 2009). However, the priority placed on recovery by policy makers and user groups means that it is likely that older people's mental health services will need to respond to the recovery agenda. In doing so, they will need to be clear about whether the concept needs to be modified.

In this paper, we present a conceptual framework of recovery for users of older people's mental health services derived from an exploration of the beliefs and experiences of service users and carers through a series of in-depth qualitative interviews. We have aimed to investigate two research questions:

(1) Are components of recovery identified by working age adults meaningful to older people with mental health problems?
(2) Are there additional components of recovery which are specific to dementia?

We have sought to identify key similarities and differences from the existing concept of recovery, and have explored the emerging practice implications.

Method

Sample and setting

Participants were over 65 years of age and were users of older people's mental health services. Participants were recruited via mental health professionals across 11 community mental health teams in South London. Staff were asked to approach service users on their caseloads about potential involvement in the interviews and were given a study information sheet to assist with this task. The recruitment strategy was to include as wide a variety of users as possible. All service user participants were, in the judgement of staff, able to give informed consent, and all had a clinical diagnosis.

Service users with dementia were asked to identify their main caregiver, if they had one, who was subsequently approached about involvement in the study. Carer participants were family members and partners providing informal care, and included five female and five male carers. Eight of the service user and carer participants were dyads.

Procedure

Ethical approval was obtained from the National Research Ethics Service (London, Camden & Islington) in November 2009.

Topic guides for service user and carer participants were developed from a review of the recovery literature in relation to working age adults. Key topics included the following: day-to-day life, use of time, impact of illness, coping mechanisms, and future plans and goals.

The majority of interviews were carried out in participants' own homes. Service user and carer participants were interviewed concurrently in different rooms. Written consent was obtained, and interviews were conducted by two researchers (S. D. and D. N.) between February and November 2010, and lasted between 45 and 60 minutes.

Analysis

Thirty interviews were undertaken, audio-recorded, transcribed verbatim and checked for accuracy. The transcripts were then analysed using grounded theory techniques. Grounded theory is a systematic methodology, which identifies patterns of meaning

from data to construct theory (Glaser and Strauss, 1967).

The process of analysis started with descriptive coding whereby, the researchers (S. D. and D. N.) independently coded three transcripts to identify preliminary themes, which they jointly reviewed with an independent qualitative researcher (J. M.), and agreed an initial coding framework.

The remaining 27 transcripts were coded using constant comparison techniques, which involved reviewing coding and data between existing and new transcripts in order to; (i) identify new codes, (ii) check the use of codes for consistency, and (iii) explore relationships between different codes. Emerging themes were reviewed with the qualitative researcher (J. M.) and also a service user in respect of her lived experience. An initial conceptual framework was developed, and eight final focused interviews were undertaken and analysed using theoretical sampling to refine our understanding of emerging themes and produce a final conceptual framework. The analysis was supported by the use of Nvivo 8 (QSR International, 2008).

Results

Participants

Thirty-eight interviews were completed, comprising 28 service user participants and 10 carer participants. Table 2 characterises the service user participants.

Conceptual framework

A conceptual framework for the experience of recovery for users of older people's mental health services developed from the analysis is shown in Figure 1. An overarching core category of 'continuing to be me' was identified, which encompassed the following five themes: Identity, Impact of Illness, Making Sense of the Experience, Dealing with Illness and Recovery of Self.

Core category: 'continuing to be me'

The single core category identified from the analysis was 'continuing to be me'. This related to the permanent and

Table 2 Socio-demographic and clinical characteristics of service user participants

| Characteristic	Type	Number (percentage)
Gender	Female	16 (57)
	Male	12 (43)
Age	65–75 years	12 (43)
	76–85 years	13 (46)
	86 years	3 (11)
Ethnicity	White British	20 (71)
	White other	3 (11)
	Afro-Caribbean	2 (7)
	Asian	3 (11)
Living situation	With spouse	9 (32)
	Living alone	14 (50)
	Supported housing	2 (7)
	Lives with family	2 (7)
	Residential care	1 (4)
Diagnosis	Dementia	11 (39)
	Psychosis	3 (11)
	Affective disorders	14 (50)
Mini mental state examination score for participants with dementia	21–30 (mild impairment)	7 (64)
	11–20 (moderate impairment)	4 (36)
Previous use of mental health services before 65 years	Previous use of services	9 (33)
	No previous use of services	19 (67)
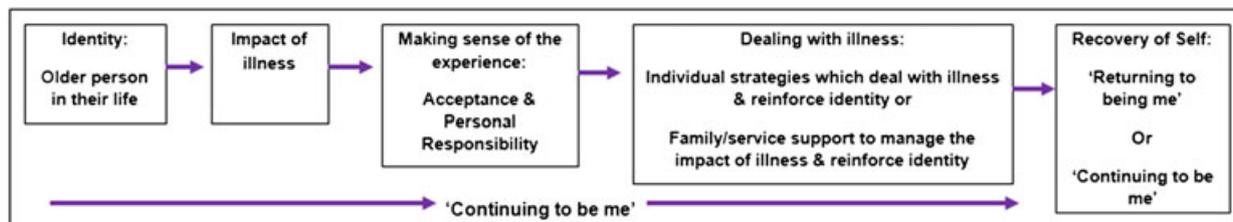
Figure 1 Conceptual framework for recovery in older people with mental health problems.

established sense of identity, which service user participants held, and its significance in their experience of mental illness. Service user participants had a clear sense of who they were and how they defined themselves. This sense of 'who I am' permeated all of the interviews and appeared to be key in buffering the impact of the illness. The goal of 'continuing to be me' or 'getting back to being me' was evident in the activation of coping strategies, which reinforced a sense of self, and as a measure of progress and successful outcome.

Theme One: Identity

All of those interviewed had an established and enduring sense of identity, and all described, in detail, the history of their lives before becoming unwell. The journey of recovery from mental illness appeared primarily to be connected to the extent to which the pre-existing sense of identity could be maintained or regained.

Theme Two: Impact of Illness

(1) Loss of established roles, social networks and occupations

Participants discussed the overwhelming sense of loss, which accompanied their experience of mental illness. Participants with both functional and organic illnesses described losing interest in the people and activities, which were important to them, and withdrawing from the world.

(2) Impact of co-existing physical illness

Participants with both functional and organic mental health problems described difficulties with their physical health, which impacted upon their mental health and their ability to continue with important roles and activities. The impact of, and need to manage both mental and physical illnesses appeared to be experienced as a whole.

(3) Impact of dementia

For people with mild dementia, the impact of the illness appeared to be experienced most strongly in relation to the completion of everyday tasks and activities, as well as their short-term memories.

> 'I still do cook. I liked cooking when I was normal I did a lot of good fancy cooking... Well now I only do the basic stuff'. (No.26, female service user with mild dementia)

Participants with moderately severe dementia were unable to provide an account of the impact of their illnesses upon their lives.

Theme Three: Making Sense of the Experience

The analysis indicated that a number of processes facilitated or hindered the capacity of participants to make sense of the experience of illness. These included acceptance or non-acceptance of illness as well as perceived responsibility for recovery. Responsibility for getting better and managing the impact of illness was seen by some participants as their personal responsibility

> 'I think there are a lot of people when they have mental illness or especially depression they seem to rely on the pills and that's it. You've got to help yourself as well. You've got to push yourself to do things'. (No.2, male service user with depression)

Whereas other participants believed it was the responsibility of either mental health services or others to enable recovery.

> 'I am not very creative because I am suffering from alcoholism ...I just find that I am unmotivated and I have a terrible depression. Dr X is trying to cure it'. (No.5, male service user with depression)

Theme Four: Dealing with Illness

A number of mechanisms were identified by participants, which had a dual role of both mitigating the impact of illness and promoting continuity, therefore reinforcing a sense of identity. Predominantly, these were selected on the basis of personal preference, availability of internal and external resources, including mental health services and applied to all participants. These are summarised in Table 3.

Theme Five: 'Recovery of self'

For people who perceived that they were managing their illnesses well, a key outcome appeared to be the extent to which they felt that they had maintained or regained their sense of self. Most of those with affective and psychotic disorders saw a successful outcome following mental illness as becoming, or progressing towards being their former selves again.

> 'Getting back to being me...it was just that I was slowly reverting back to my former self really'. (No.36, male service user with psychosis)

Table 3 Coping mechanisms for dealing with illness

Coping mechanism	Includes	Example
Compensatory techniques	Use of diaries, lists and home re-organisation, practical help such as a cleaner	*'If she sends me down the shops… If she writes the items down, I'll be alright'. (No.3, male service user with mild dementia)*
Continuation of social networks, roles and meaningful activities	Continuation of existing, rather than new, social networks, roles and established activities.	*'Having loyal friends and not being completely on your own is important because when you start getting better, you've got friends to focus on haven't you?' (No.2, male service user with depression)*
Making sense of illness/using information	Finding out more about illness, fully understanding diagnosis and ways of coping. Includes information from professionals, either individually or in groups	*'I thought "thank god" I like knowing, the Alzheimer's – I know now what is me, and what is the Alzheimer's'. (No.23, female service user with mild dementia)*
Self-help activities	Undertaking activities, which are perceived to be helpful to overall health and well-being such as diet, or taking a daily walk	*'Every day, I will take a walk up to X and walk back. I do make a habit of going out'. (No.8, female service user with panic disorder)*
Being part of the world	Includes engaging with others and knowing what is going on in the world.	*I don't want to sit here all day and wait for the news to come on. I'd rather get a newspaper, I'm still part of the world..' (No.12, female service user with mild dementia*

For people with dementia, this was more commonly expressed as being able to maintain a sense of self.

Two components of recovery emerged as being specific to people with dementia:

(i) The role of spousal carers of people with dementia in reinforcing a sense of identity

For people with dementia who were married or in a long-term relationship, the impact of the illness and development of strategies to deal with the illness took place in the context of that partnership. From the analysis, it was evident that carers held a key role in either facilitating or hindering the use of coping strategies, which both mitigated the impact of illness, and provided continuity, thereby reinforcing a sense of identity – as is illustrated by the following couple:

'I don't do very much now at all apart from looking after my beloved'. (No.26, female service user with mild dementia)

Researcher: 'Can you tell me what X would see as her role?'
Carer: 'Looking after me'.
Researcher: Was it?
Carer: 'It still is'.
(No.27, male spousal carer)

(ii) The changing experience of recovery for people with dementia

From the analysis, the mechanism for maintaining a sense of self was seen to change over time for people with dementia. For participants with a mild dementia,

personal responsibility for managing the impact of illness and personally instigating coping strategies, which supported compensation and continuity, were both evident. For participants with a more advanced dementia, where the subjective sense of awareness and therefore personal responsibility had decreased, carers reported that they had gradually taken on a more direct role in managing the impact of illness as severity increased. In situations where carers had been able to reinforce a sense of personal identity through continuity, it was evident that recovery continued to take place. These additional components are presented in Figure 2.

Discussion

Analysis of 38 qualitative interviews using grounded theory methods has provided an empirically derived conceptual framework for recovery for users of older people's mental health services, with five key components. Two additional components of recovery have been identified for people with dementia.

Recovery for older people compared with working age adults

We have compared our findings with components of recovery identified by working age adults. The components of recovery, which appear to be meaningful to both groups, are as follows: (i) the impact of illness, (ii) the significance of personal responsibility, and (iii) a number of specific coping strategies, most notably using
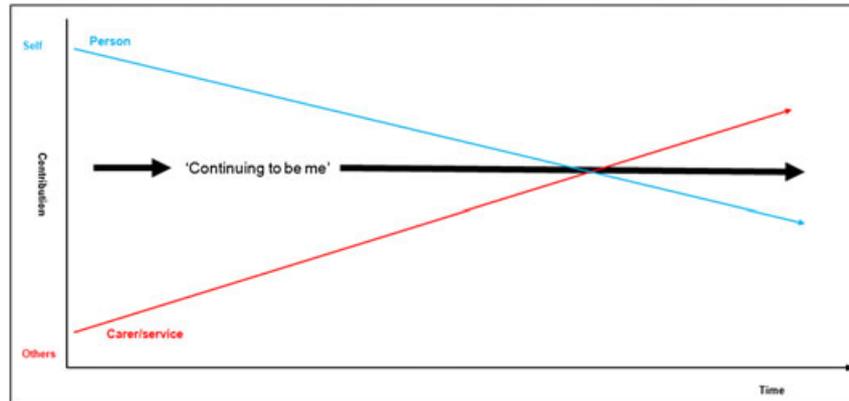
Figure 2 Additional components of recovery for people with dementia.

information, being connected to others and to the world and self-help activities.

In contrast to working age adults, the older people interviewed did not aspire to a new and revised sense of identity. Support was derived from existing long-term relationships as opposed to peer support from others with lived experience of mental illness, representing a significant difference in the sources and utilisation of support by older people compared with working age adults (Leete, 1989; Deegan, 1996; Repper and Carter, 2010).

We have identified three elements of recovery, which appear to be distinct to users of older people's mental health services:

(1) The significance of an established and enduring sense of identity in the experience of mental illness, both in terms of mediating the impact of illness and in providing internal and external resources to deal with illness.
(2) Coping strategies that provide continuity through the utilisation of existing networks, roles and activities, including peer support from long-term friendships. This finding is consistent with the literature on 'successful ageing', which proposes that the process of maintaining or adapting existing social networks, activities and roles enhances a positive and enduring sense of identity and adjustment to older age (Atchley, 1989).
(3) The impact of co-existing physical and mental illness, and the development and use of coping strategies to deal with both.

Recovery and people with dementia

The findings from this study of the importance of 'continuing to be me' and the use of strategies involving compensation and continuity to re-enforce self are consistent with research on identity and coping for people with dementia (De Boer *et al.*, 2007; Caddell and Clare, 2011; Cotrell and Hooker, 2005; Clare, 2002). Further, it is apparent that important elements of the concept of recovery as defined by working age adults hold value for people with dementia, for example personal responsibility and connectedness but that some modification is required. Two key components appear to further influence the experience of recovery for people with dementia, namely a changing balance over time from personally initiated strategies, which provide compensation and enable continuity, to support from others.

Practice implications

There are three key practice implications arising from this study:

(1) Maintenance of Identity

(a) The study highlights the need for mental health professionals to focus on maintaining the identity of users of older people's mental health services. Although a focus on identity is enshrined within the philosophy of person-centred care for people with dementia (Kitwood, 1997), this is not routinely considered for users who have affective and psychotic disorders.

(2) Promoting empowerment, agency and self-management

(a) This study has demonstrated that users of older people's mental health services do perceive themselves as being responsible for managing their own illnesses and of being able to develop coping strategies based on their own preferences and resources. This contrasts with the working practices evident

within some older people's mental health services, where the principles of empowerment, agency and self-management are not routinely promoted (Bowers *et al.*, 2005). Similarly to mental health services for working age adults (Farkas *et al.*, 2006, Boardman and Shepherd, 2009), wider system change within older peoples' mental health services is indicated.

(3) Facilitating the process of recovery for people with dementia

(a) The need to take a staged approach to supporting the recovery of people with dementia is highlighted from this study. Work with users and carers about practical strategies to promote agency, compensatory techniques and continuity is indicated.

Limitations of the study

There are three main limitations to this study.

Firstly, only participants who were willing and able to provide an account of their experiences took part. This should be acknowledged as a potential limitation, as it is possible that this group of participants may have been more likely to have an established sense of self and have been more adept in managing and living well with their illnesses, and as such may not be fully representative of users of older peoples' mental health services.

Secondly, the majority of those interviewed (67%) had not experienced mental health problems until later life. Their sense of identity had developed for the most part without mental illness and without connection with mental health services. It is not clear whether this framework can be applied to older people with enduring mental health problems that have been present throughout adult life and are users of working age adult services.

Finally, as the participant profile within this study is intentionally broad, in-depth practice implications for specific groups of service users, for example, those with a recent diagnosis of early dementia, is limited.

Conclusions

This is the first study to empirically explore the relevance of the concept of recovery for older people with mental health problems compared with working age adults. We have demonstrated that an established sense of identity and continuity are critically important to recovery for users of older peoples' mental health services.

This study has potential value in encouraging older peoples' mental health services to more actively respond to the narratives of service users and carers, and in doing so, consider how the principles of empowerment, agency and self-management can be embedded within their services.

This study also enables older people's mental health services to be clearer about where they may need to deviate from an established recovery policy agenda (Department of Health, 2011), which has been developed without detailed consideration of differences in recovery across the life-span. There is a need for the recovery policy agenda to be revised to ensure that it works for people with mental disorder of all ages, not just those of working age. If it is not, then it runs the risk of generating services that work less well for older people than for people of working age and so embedding rather than addressing discrimination.

Conflict of interest

None declared.

Key points

- Recovery holds value for older people with mental health problems, and is primarily concerned with maintaining or regaining a sense of identity.
- Three components of recovery appear to be distinct to older people; the significance of an established and enduring sense of identity, coping strategies which provide continuity and compensation and therefore reinforce identity and the impact of coexisting physical illness.
- Two additional components of recovery for people with dementia are the changing experience over time and support from others.

Author contributions

All authors contributed to the conception and design, drafting and revision of the article, and gave approval to the final version. Stephanie Daley is the Principal Investigator.

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