rethink

Getting back into the world

Reflections on lived experiences of recovery

Rethink recovery series: volume 2

by Sarah Ajayi, Julie Billsborough, Terry Bowyer, Pippa Brown, Alice Hicks, John Larsen, Peter Mailey, Ruth Sayers, Roger Smith

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Working together to help everyone affected by severe mental illness recover a better quality of life

Aims of presentation

- To present key findings from a study on lived experiences of mental health recovery
- To present our partnership method where 7 people with personal experience of mental illness were supported as researchers by the Rethink research team
- To invite debate over what makes recovery possible, and everyone's roles in making it a reality

The Project Team

L-R: Julie Billsborough, Alice Hicks, Peter Mailey, Ruth Sayers, Terry Bowyer, Pippa Brown, Roger Smith, John Larsen, Sarah Ajayi, (Front) Alison Faulkner

Project funded by: AstraZeneca

Method

- Seven people with personal experience of mental illness and psychiatric treatment were trained and supported as researchers.
- In-depth semi-structured interviews with 48 people with personal experience of mental illness and psychiatric treatment.
- Involvement researchers used personal experiences and insights in the analysis of data.

Participants

- 48 participants were recruited from across England
- Participants ages were from 18 to above 65 years
- There was a balanced gender representation
- 90% described themselves as White British
- The participants all had substantive experience of mental health problems and treatment, and 64% reported they had had a diagnosis of severe mental illness

Table 2: Profile of participants (n=48)

		Number of participants	Percentage of Participants
Gender (n=48)	Female Male	26 22	54% 46%
Age group (n=48)	18-24: 25-34: 35-44: 45-54: 55-64: 65-74:	3 6 11 16 9 3	6% 13% 23% 33% 19% 6%
Ethnicity (n=48)	African Asian Black British / Caribbean White British White Other	1 1 1 43 2	2% 2% 2% 90% 4%
Region (n=48)	London South East South West Eastern North West	12 5 15 4 12	25% 10% 32% 8% 25%
Diagnosis (n=47)	Bi-polar Depression Anxiety Schizophrenia Schizo-Affective Eating Disorder Personality Disorder Dual diagnosis Other	20 17 17 10 5 7 7 1 6	43% 36% 36% 21% 11% 15% 15% 2% 13%
Ever had a diagnosis of SMI (severe mental illness)? (n=47)	Yes No	30 17	64% 36%
Ever used medication to manage mental illness? (n=47)	Yes No	45 2	96% 4%
Lives alone (n=47)	Yes No	20 27	43% 57%
Marital status (n=45)	Married Widowed Separated Divorced Cohabitating Single	11 3 2 4 5 20	24% 7% 4% 9% 11% 44%

Interviews

We asked people…

- How they saw themselves in relation to mental health
- Did they experience any turning points in their lives?
- Were there helpful and unhelpful people and things?
- How do they understand recovery?
- What are their personal gains and achievements?
- Do they have recommendations for others?
- Reflection on the interview itself

Process of analysis

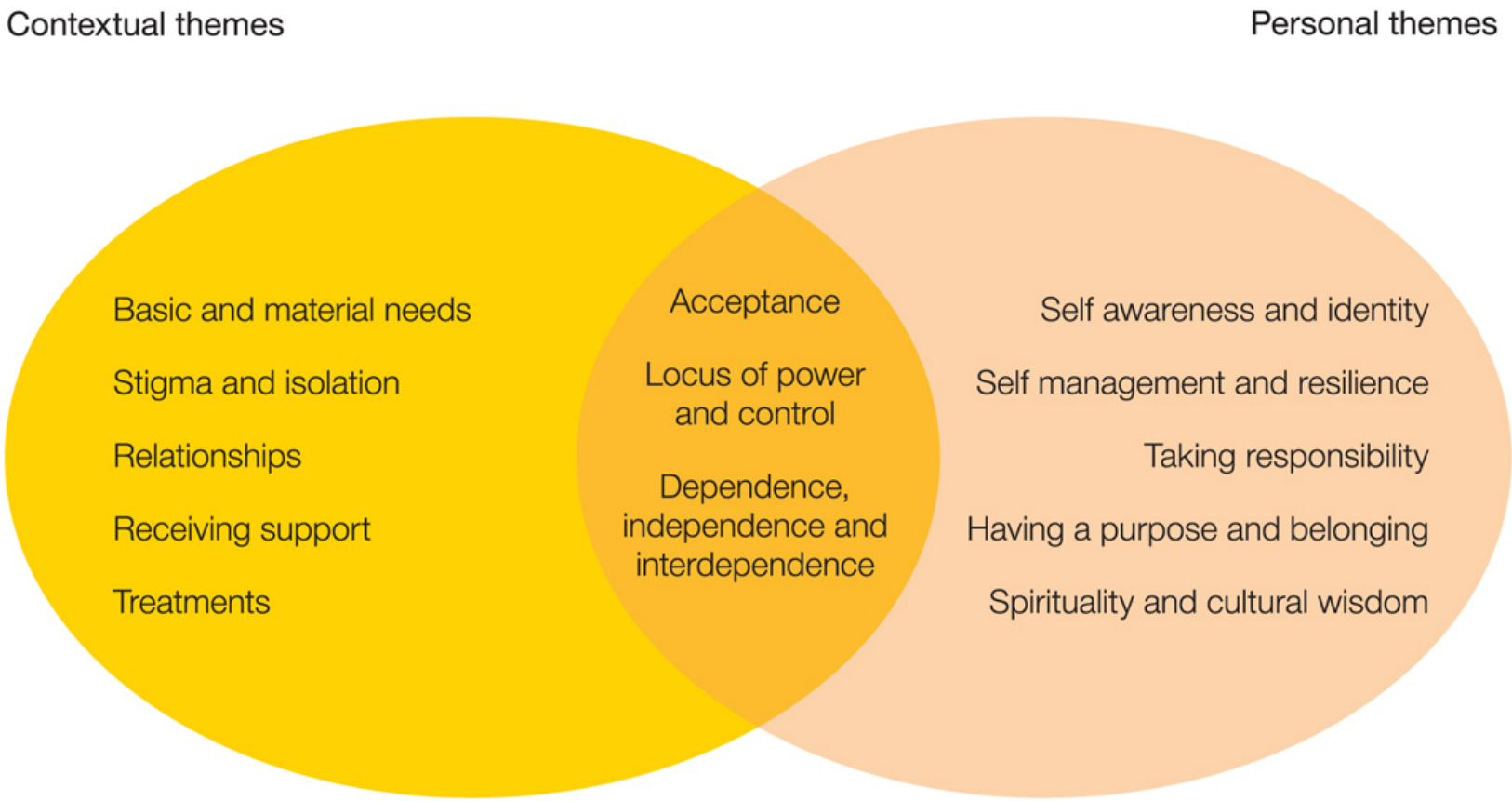
1. Group construction of themes and structure for the interview guide
2. Using personal insights to ask follow-up questions during interviews
3. Involvement researchers writing post-interview personal reflexive notes
4. Thematic analysis of interviews drawing on the reflexive notes
5. Group construction of analytic framework identifying key themes
6. Involvement researchers identifying data for themes and including personal reflections
7. Group validation and edit of collated write-up of themes

Findings

- We found 10 key themes that could be grouped in:
  - **Contextual themes**
  - **Personal themes**

- We found 3 **recovery mediators**, that represent particular life challenges binding together the contextual and personal

Figure 3: Recovery mediators of contextual and personal themes



1. Basic and material needs

- Recovery crucially depends on issues such as secure accommodation, financial freedom and certainty, and basic human rights and being a citizen.

> Getting practical things sorted... [that was] help that I really needed. Once you get it together on a practical level, then everything else sort of falls into place a little bit more (RGS04, 645-649).

2. Stigma and isolation

- Prevailing societal perceptions and attitudes impact on the person in recovery. Stigma blocks recovery and leads to a low mood and isolation.

When you're depressed, [at] my worst, I felt totally alone. You know, there's nobody... and disconnected from people.

(AH05, 946)

3. Relationships

- Positive relationships where the person feels supported and encouraged are essential to give the person the confidence to move forward. The challenge for people in recovery is to distance themselves from negative relationships, while building and nurturing supportive relationships.

4. Receiving support

- It is essential to engage with people to receive support when unwell.
- Mental health professionals are required to take a human approach.
- Mutual and informal support networks can play a critical role in maintaining recovery.

5. Treatments

- Psychiatric hospital was described as a negative experience, although some felt that it had been necessary at the time.
- Medication was by most considered an essential part of their treatment, but one that should not stand alone: the right type/dosage and personal choice were highlighted.
- Talking therapies were described as an important part of the treatment package.

6. Identity and self-awareness

- Recovery involves experiencing a greater sense of self and confidence in one's own identity. This involves issues such as understanding the illness and developing relationships and social roles to support personal growth.

You've got to really work out what society has done… you've got to say 'sod it, chuck that'. I mean, you know... and the enjoyment is becoming yourself and then becoming your full measure. (PJB01, 1233-1239)

7. Taking responsibility

- Participants described the importance of themselves taking an active role to engage in recovery. This can be frightening, and it is important to have personal incentives and adequate support in the process.

..at one point I didn't want to do anything that made people think that I was recovered, because they'd expect something. Or they might expect too much from me. So you know, I held myself back as well, because recovery was too frightening. (PJB03, 643-654)

8. Self-management and resilience

- It is important to develop knowledge of personal illness triggers and to learn from others – coping strategies can be very individual. Living through longer periods of wellness builds resilience and confidence in recovery.

A place to start is somewhere very small, perhaps a sock drawer, sort out your drawer, sort out under the sink, get that absolutely right. (JB02, 575-578)

9. Having a purpose and belonging

- Being part of something bigger and being recognised by others is essential. Too much pressure can have a negative effect – important to find roles and challenges that are appropriate given individual circumstances.

Being occupied. Having… having a, you know, some kind of self worth and feeling that you are valued by other people. This sounds as really big-headed that you need all of these things. But I found that crucial: me feeling valued. (PJB03, 487-493)

10. Spirituality and cultural wisdom

- For some, feeling close to God or using spiritual techniques could be a source of comfort and help put the mind at rest. Finding the right level of involvement with spiritual issues is important, but rarely professionals offer support in spiritual matters.

Recovery mediators

- Ways in which contextual and personal factors work together
- Help us to see the importance of situation and resources available to the person
- Describe the dilemmas and challenges of daily living that meet the person in recovery
- Give options regarding the individual's mix of contextual and personal factors

a. Acceptance

- It is crucial that the person feels accepted by others and finds a way to accept themselves and their condition in order to progress towards recovery.

I was terrified of it really, before. I think I was scared of being crazy or nutty, scared of the way I was acting. But now I'm not. Maybe that's changed me. I just accept that this is the way I am, and once you've accepted it, then you can work with it.

(RGS06, 1819-1825)

b. Locus of power and control

- Mental illness often leaves the person with almost no control over their own lives.
- Recovery involves (re-)gaining control, often starting with small steps and self-management techniques.

Recovery is about getting things together. Making something of yourself, sorting your life out, where you get back into the world. (RGS02, 1526-9)

c. Dependence, independence, and interdependence

- Often people with mental illness feel dependent on others and on treatments.
- Finding a balance between regaining independence and recognising interdependency is essential to recovery.

(quote on next slide...)

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I was asked to escort this lady that was going to the computer class but she found it really difficult to get out... I thought: ‘oh god, I can’t do that. I know, I’ll go to [named staff] and I’ll go to [other named staff] and they’ll sort of kick up a fuss and tell the tutor off.’ And they just thought, ‘oh, it’s a very good idea.’ [I thought:] ‘No, it’s not a good idea, it’s a terrible idea.’ Anyway, I supported her to get to the class and I felt so good that I... I didn’t feel as I could support myself and it just made me feel that, you know, that I had something to offer. (PJB03, 82-115)

Conclusion

- The person is at the centre of the process of recovery
- Contextual and personal factors both play a role – and it is important to understand the complexity of this.
- The recovery mediators describe the challenges meeting the person on a recovery journey

There is no ‘easy fix’!

Discussion – some suggestions..

1. Your thoughts about the design and findings of our recovery research project?

2. How do our findings compare with your experience of what promotes and brings about recovery?

3. What is your role in recovery?

4. How are your efforts dependent on contextual or personal factors?

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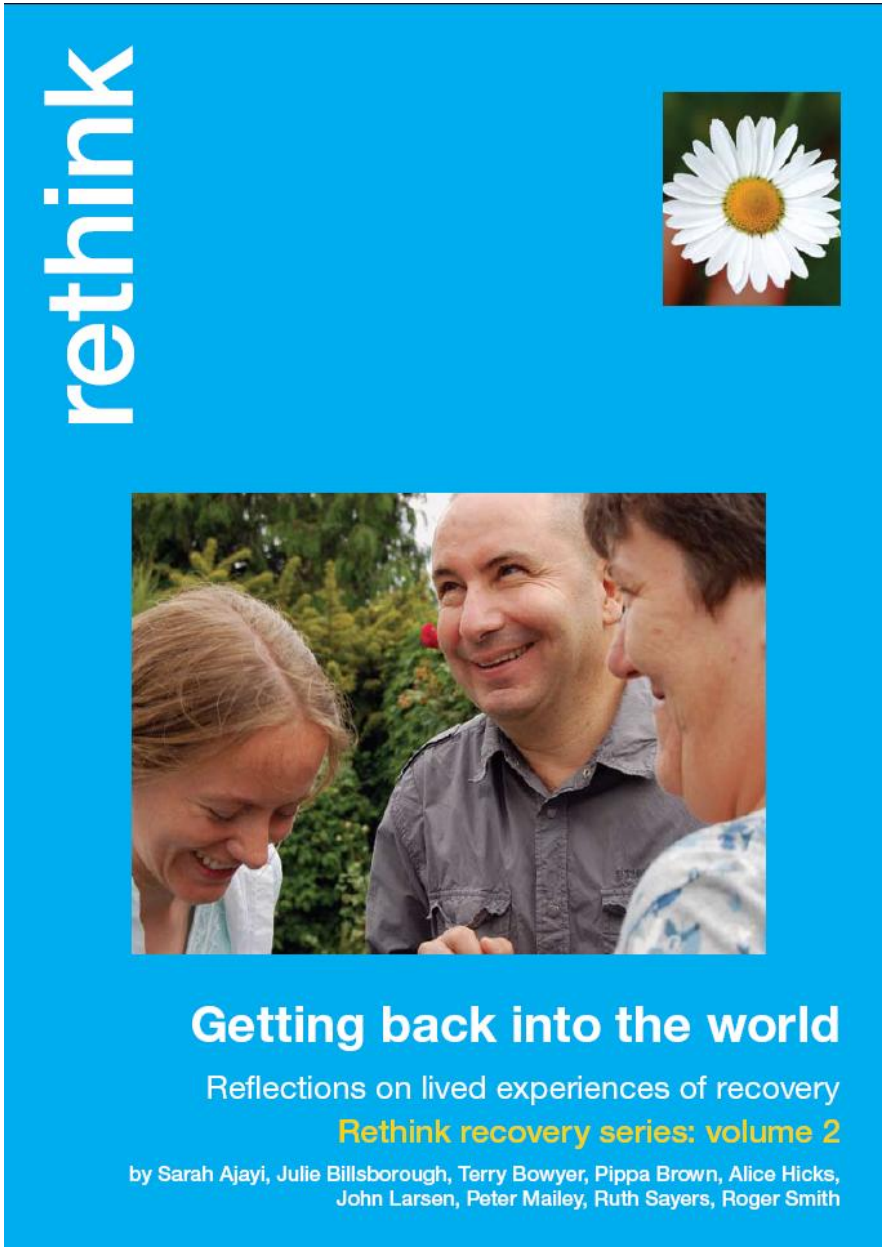
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