



Ups and downs: experiences of support in bipolar

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Plan of presentation

Background - study focus

Reflexive service user research methodology

Study design

Interim findings

Some conclusions



Background

People with a diagnosis of bipolar disorder have reported different experiences of support when they are depressed ('down'/'low') and when they are manic ('up'/'high').

Are the person's support needs different when up or down?

Is formal and informal support and treatment different when up or down?



Research questions

What are the experiences of support and treatment when up and when down?

Do these experiences differ and reflect different types of need?

Do people get support from different mental health professionals and informal support people when up and down?



Methodology: Service user research



www.rethink.org

Team of five Involvement Researchers

- Personal experience of using mental health services

- Previously worked together on previous research study

Support from the Research Team

- Coordination

- Facilitation

- Payment, task specific (hourly research officer rate)

Support from external Service User Research expert



Reflexive service user research - 7 step approach

1. Group construction of themes and structure for interview guide and web questionnaire
2. Reflexive exchanges through dialogue about experiences during interviews
3. Involvement Researchers writing post-interview personal reflexive notes
4. Thematic analysis of own interview drawing on reflexive notes
5. Group construction of analytic framework considering full data set - 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



Use of personal experience in reflexive approach

Methodological transparency

- Validity and reliability check for bias
- Critical perspective on the construction of knowledge

Personal experience as data in themselves

- Providing richness and detail directly from lived experience
- Using insight from personal experience to challenge other data and conclusions drawn
- Keeping research real and close to the reality of lived experience



Study design

Individual interviews

- People with experience of bipolar diagnosis (n=16)
- Support people for people with experience of bipolar diagnosis (n=11)

Questionnaire (internet based) – responses:

- Experience of bipolar diagnosis (n=145)
- Experience of other mental health diagnosis (n=92)
- Supporters of people with experience of bipolar diagnosis (n=33)
- Supporters of people with experience of other mental health diagnosis (n=44)



Key themes

- Self management
- Support provided
- Being listened to
- Being affirmed
- Being encouraged
- Use of medication
- Own attitude
- Others' attitude
- Surroundings/ environment



Self management techniques – specific to prevent up or down

Prevent UP

- Avoid stimulation
- Pausing, taking time out
- ‘Stop and think’ - (being aware of your own situation)
- Keeping a journal
- Diet
- Avoiding social contact (future damage limitation)

Prevent DOWN

- Mindfulness/ meditation
- Having routine
- Avoid pressure
- Relax
- Keeping active/ busy
- Exercise
- Having a goal – future orientation

These were not necessarily exclusive to up/down

– just more likely to be mentioned in up or down



Becoming up or down

- Importance of taking action early on before acute crisis develops
- Being aware of own early warning signs

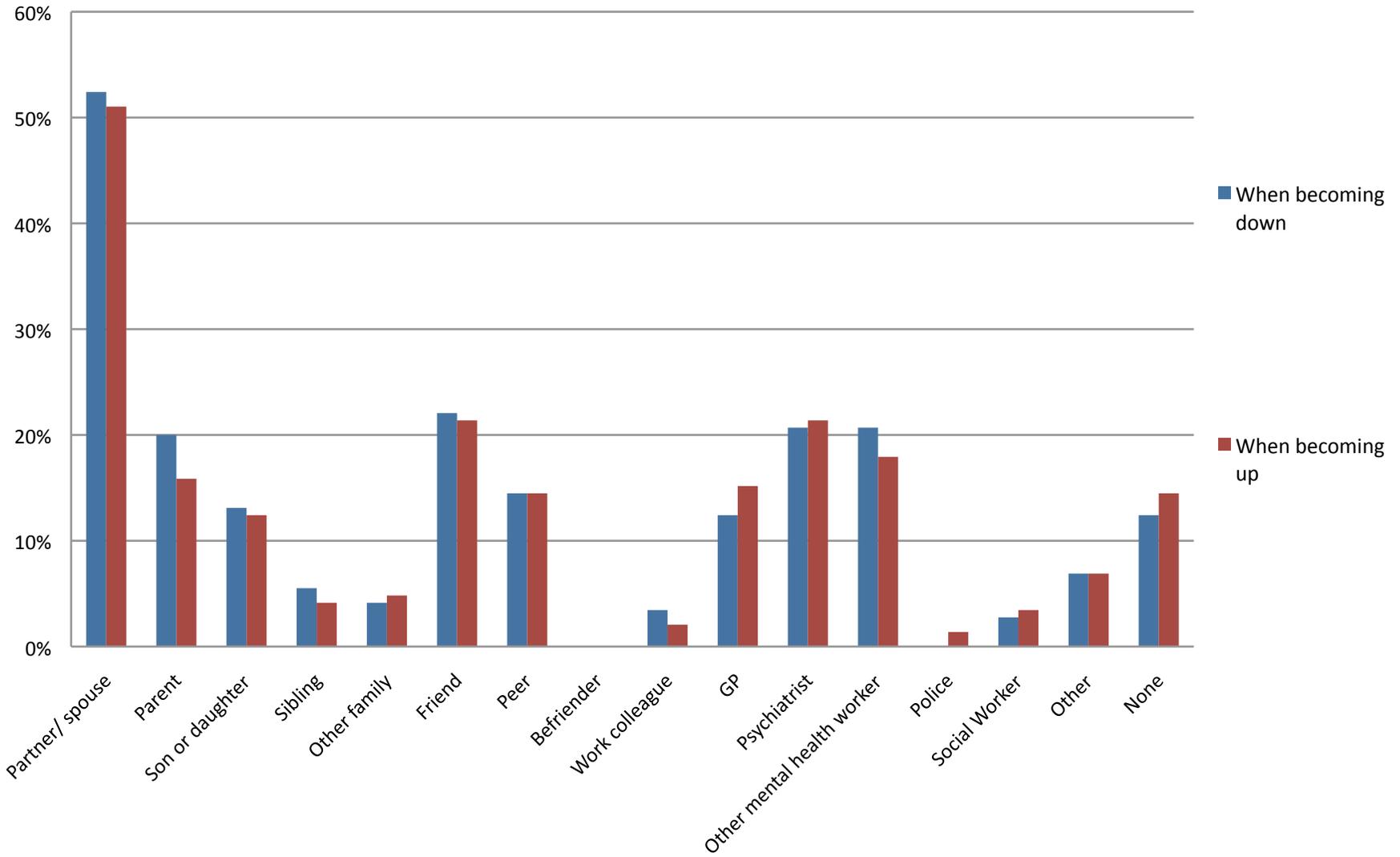


Support provided

- Getting support from others to be aware of early warning signs
 - Mental health professionals
 - Informal support people play important role!



Do you have someone who will notice and take action when you are becoming down/up? (n=145)





Use of medication

Concern over: medication as only option

Up/High/Mania

Medical intervention features centrally in response to becoming up – either urgently start or stop taking a particular psychoactive medication

Several interviewees described becoming manic in response to taking antidepressant medication

Down/Low/Depression

Medical intervention features less prominently

Nature of medical intervention is more a case of longer term management



Nature of the supportive relationship

Being listened to

Being affirmed

Being encouraged



Being listened to

- Understanding the person, what makes them 'tick' – interests, what they enjoy
- Trust – lack of mistrust
- Positively engaging with conversation (responding)
- Feeling safe
- Feeling valued
- Reassurance
- Making suggestions to influence behaviour in a positive light
- Non-judgemental



Attitude – others'

Stigma is a key barrier to positive engagement with and experience of mental health support and treatment

Effectiveness of the supportive relationship is significantly shaped by the supporting person's attitude (see points above)



Attitude - own

General

Motivation – you only engage in your own recovery if you feel personally motivated

Up

Recurrent theme in our data that people enjoyed the up and that they were reluctant to seek support or treatment to prevent/ end the up

Enjoying up does not apply to everyone



Surroundings/ physical environment

The quality of your accommodation

The condition of the hospital ward environment
(alternative crisis intervention called for)

Importance of nature, walks and 'fresh air'



Recommendations for mental health professionals

- Act early
- Listen
- Empower
- Build support



Act early

- It is essential to provide early preventative intervention to promote wellness and reduce escalation of crisis.
- This is especially important when a person is becoming manic.
- Too often interventions come too late.
- Be aware that people are likely to have different support need



Listen

- Both patients with bipolar and their carers feel that health professionals are often not good at listening to them.
- This is a general issue in respect to feeling that the health professional really understands them as a person and their particular concerns and interest.
- Without such a person-centred *active listening* approach the patient often feels unsupported.
- More specifically both patients and carers experienced health professionals not taking them seriously enough when there were warning signs of mania.
- Health professionals have to listen and act accordingly to prevent escalation of crisis.



Empowering
people.

Coaching for mental health recovery. By Rani Bora



Empower

- People with bipolar are better able to manage their condition and take appropriate health promoting action after gaining knowledge about mood disorder coping strategies.
- Learning about personal early warning signs, strategies and how different medication might impact on them, people are more empowered and feel more in control and positive.



Build support

- Carers and other informal supporters can help ensure appropriate action is taken to promote well-being and so avoid escalation of crisis.
- This is particularly important as people are not always aware of themselves becoming unwell – this may particularly apply when becoming manic.
- Health professionals need to be aware of how friends and family might be able to offer support and support and encourage this.
- Health professionals also need to be aware that family members need support too



Dissemination plans

- Article in academic journal
- Conference presentations
 - Refocus on Recovery Conference (done in March 2012)
 - Recovery Research Network meeting (now!)
 - Qualitative Research in Mental Health Conference (July 2012)
- Booklet/flyer with practical guidance for:
 - People with personal experience of bipolar
 - Non-professional support people
 - Mental health staff
- Input into revision of NICE guidance for bipolar disorder
- Puppet show video
- 'Talking heads' video