

Article

Depression recovery from the primary care patient's perspective: 'hear it in my voice and see it in my eyes'

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ABSTRACT

Purpose This paper aims to contribute to the discussion about the concept of recovery from depression from the patient perspective.

Methods A structured, computer-assisted telephone interview of 576 participants from the Australian diamond cohort study who were asked, at the one year follow-up, how they would know if someone had recovered from depression. The responses were thematically analysed using a modified grounded-theory approach.

Results Participants found the question challenging on a number of levels, relating to the definition of recovery, the subjective nature of getting better from depression, pessimism about the possibility of recovery and concerns that people hide how they really feel. Participants reported observation and human interaction as crucial to deciding if recovery had occurred. This led to

three broad groups of indicators for recovery: a person's actions, their appearance and their thoughts and feelings.

Conclusions Australian primary care patients with depressive symptoms report using observation and human interaction when trying to decide if someone is getting better from depression, leading to a broad range of indicators of recovery that include, but are not limited to, the traditional symptom-based definitions of depression remission. This data suggests that patients have a rich variety of ways of describing recovery, supporting a call for more patient-centred approaches to setting goals for depression recovery in the primary care setting.

Keywords: depression, primary care, recovery

Introduction

Epidemiological research has established depression as a growing global health burden.¹ General practitioners (GPs) have been urged to improve their detection of depression² and to aim for full remission of depressive symptoms as the goal of treatment.^{3–5} The use of measurement scales that assess severity of symptoms have been promoted to GPs in

a number of countries as a way of routinely screening, assessing severity and monitoring depression outcomes.^{6–9} Nevertheless, recent primary care guidelines acknowledge the limitations of over-reliance on a symptom-based approach, as it underemphasises the complex biological, psychological and social factors that influence response to treatment.¹⁰ Some

guidelines have therefore taken a more holistic approach by including level of function and quality of life as indicators of recovery.¹¹

This lack of clarity about what constitutes recovery from depression is not surprising, given the current debate about the concept of depression itself.^{12,13} Added to this is the uncertainty about whether depression is a 'disease', an 'illness', an 'experience' or all three,¹⁴ creating some confusion about what exactly the person is recovering *from*. The psychiatric literature commonly takes a 'disease' approach, calling for greater precision in labelling of the change points of remission, recovery, relapse and recurrence that a patient may experience in the course of treatment for depression.^{15,16} Yet lay accounts of depression are often highly contextualised, creating tensions between the subjective experience of 'depression' and acceptance of a biomedical model as a pathway to recovery.¹⁷ Thus, there remains no clear consensus on what constitutes recovery, with clinical trials of antidepressants and psychotherapy continuing to focus on symptoms, while interventions in 'real-world' settings seek a measure of change that is clinically meaningful, giving prognostic information for each individual receiving treatment.^{18,19}

Furthermore, when measurement is used to determine depression recovery, it is assumed there is a cut off point at which recovery occurs. This suggests that there is a discrete boundary between someone who is ill and someone who is well. Such an approach has been criticised for objectifying the patient and neglecting the importance of psychological and social aspects of the person's lived experience.²⁰ In primary care, a statistical approach to normality, requiring value judgements and arbitrary cut off points, might be impractical and inappropriate.^{21,22}

The over-reliance on objective assessments of depression recovery is reflected in the limited knowledge available about the process of recovery, particularly as a lived experience of the person with depression.²³ There is some evidence that a depressed person's health beliefs (in particular regarding health locus of control) influence recovery from depression.²⁴ Also, the idea that people with depression might benefit from taking control of their own recovery was born out by in-depth interviews of people with a long history of depression who had recovered.²⁵ Mental health service users have generally expressed a preference for concepts such as hope, choice and empowerment to be included in definitions of recovery, which may appear at odds with the biomedical emphasis on absence of symptoms.²⁶ So how relevant is full remission of symptoms as a goal for people experiencing depression? One study addressing this question surveyed 535 psychiatric outpatients with the diagnosis of major

depression. These participants rated a list of factors they considered important in determining remission. Absence of symptoms of depression was only one of several responses, outvoted by the following factors; presence of positive mental health, a return to usual level of functioning and feeling like your usual self.²⁷

Regarding depression recovery in primary care patients, depressive symptoms, health status and quality of life measures have been shown to correlate with each other.²⁸ More recently, a study looking at depression outcomes over time in primary care patients receiving antidepressants demonstrated that different outcomes are not only of different magnitude, but also peak at different times, concluding that depression remission is more complex than current guidelines suggest.²⁹ Yet within the literature regarding depression outcomes, little is known about what primary care patients who have experienced depressive symptoms would describe as the goal of treatment. This paper addresses this gap by reporting on what Australian primary care patients with depressive symptoms have to say about recovery.

Methods

The data for this study comes from an open-ended question within the one-year follow-up structured interview of a cohort of randomly recruited primary care patients with depressive symptoms. These patients are part of a large mixed methods study, the *diamond* project; a prospective, longitudinal cohort study of patients with depressive symptoms from 30 primary care practices in Victoria, Australia. Full details of the study methods are published elsewhere.³⁰

The participants were 576 people who met the criteria of 'probably depressed' based on a Centre for Epidemiologic Studies Depression (CES-D) scale score of ≥ 16 . The structured interview, developed by a multidisciplinary research team with expertise from anthropology, primary care, psychiatry, psychology and sociology, aimed to collect accounts of living with depression and experiences of health service use, and included the question 'How would you know that someone had recovered from depression?'. The recovery question was field tested (by CJ) on a small sample, before being piloted with the first 20 participants. The question was modified slightly based on this feedback. During 2006, graduate level trained research assistants administered the interview (lasting from 45 to 60 minutes) over the telephone. Responses were typed directly into a computer database. (RK led the development of the interview

questions and training sessions, while CJ participated in the training and conducted 20 of the interviews.)

The textual data from the recovery question was imported into the data management package NVIVO 7.³¹ This facilitated an iterative process whereby, during the initial open coding, memos regarding specific codes and annotations related to specific text could be organised in a logical, easily accessible manner.³² Following open coding, connections were made between the different categories (axial coding) and these connections were organised under key headings (selective coding).^{31,33,34} Thus, the concepts reported here emerged from the data, rather than adhering to a pre-existing theoretical framework.³⁵

Ethics approval for the study was granted by The University of Melbourne Health Sciences Human Ethics Sub-Committee.

Results

Here we begin by illustrating the complexities of the notion of recovery from depression for these participants. Second, we present the methods (or processes) people use to decide if someone has recovered from depression. Finally, we report on the specific indicators of recovery from the participants' perspective.

Participant demographics

Five-hundred and seventy-six participants representing a broad range of depression severity³⁰ completed the interview. The age range was from 18 to 75, with the majority (74.1%) between the ages of 35 and 64. Seventy-one percent were female, 46.5% were married and 50% had had some form of tertiary education (46.5%). The majority were in paid employment (58.1%) but approximately one-third stated that benefits were their main source of income (33.7%).

Of these participants, 484 (84%) responded to the recovery question. Apart from those who had inadvertently skipped or chose not to answer, 27 of the non-responders came from the small number of participants (51/576) who had stated earlier that they disagreed that people could get better from depression.

Recovery: a challenging question

Despite not being explicitly asked to provide accounts of their own experiences, one quarter of the

participants (109/484) chose to speak of their own experiences of recovery. Some found it problematic to make a judgement on recovery for other people:

'well ... uh ... well for me, I know how I feel inside ... for someone else. [A] difficult question to answer.' (Female, age 54)

In addition to the ambivalence participants expressed regarding who is best placed to determine recovery, they frequently reported that describing recovery was challenging:

'That's a tricky question. That's a very tricky question.' (Male, age 53)

One difficulty related to questioning the very possibility of recovering from depression:

'Oh, yeah, no, I don't think you ever recover from ... I think it's manageable, I think if you have a tendency towards depression, I believe you always have it, I don't think you'll be rid of it, I, I think it will always come back to bite you.' (Female, age 39)

The 'subjectivity' of the experience of depression and recovery also led to scepticism that another person could determine recovery:

'You can't can you? Um, um, I mean for me it's like "what's the difference between the external and the internal?", so if it's my friend, I just saw the external.' (Female, age 42)

There was also a distinction between the notion of recovery and the 'management' of depression with medication:

'Um, I don't think you totally get over it, the doctor sort of said to me, I'd probably be on medication for life, just manage it.' (Female, age 38)

Some, however, concluded that this 'managing' was, in itself, a form of recovery:

'I don't honestly think that you can say that I'm never depressed anymore, but you can work pathways around the problems so you don't end up in crisis. So seeing people managing it and getting a lifestyle that they want is a recovery.' (Female, age 43)

Another layer of complexity in determining recovery was the view that people experiencing depression often hide it from others. Whether talking about themselves or others, more than 10% of participants (62/484) specifically commented that people with depression disguise their suffering, implying that this would complicate 'knowing' if someone had recovered from depression:

'You don't – I don't believe that you really can tell. I know with myself that I'm very good at putting

on a show. But when I'm within my own four walls only I know how I feel. I could hide it from my husband. I'm very good at putting on a show if I need to.' (Female, age 36)

The process of determining recovery

Despite the view that recovery was a subjective experience, participants offered propositions about *how* they assessed recovery in others, involving either interaction with or observation of the depressed person. Recovery was placed in a broader biographical context, whereby recovery was 'measured' in relation to the notion of the person's self before depression:

'Well you'd need to know them beforehand. You'd need to know them well over a long period of time.' (Male, age 63)

The quality of the interaction was often emphasised:

'Umm, talking to them, getting to the bottom of how they're feeling, you can't take everything at face value, getting into their mind and knowing what's going on in their head.' (Female, age 26)

In keeping with the assertion that people hide their depression, participants stated that the person experiencing depression would need to *tell them* they had recovered:

'I suppose that only if someone had told you. I suppose if you can call it that, it's a disease that they can keep hidden, so maybe you'd only know if they'd spoken about it.' (Female, age 32)

Looking for expression through the body was another important way of 'knowing' a person has recovered:

'The look in their eyes really. The mouth can speak words but the eyes tell you what's really going on.' (Female, age 59)

What constitutes recovery from depression?

In addition to describing the processes used to decide if someone has recovered from depression, participants offered a number of accounts about *what* constitutes recovery from depression. We categorised these responses into three broad categories; ways of doing, ways of appearing and ways of thinking and feeling.

Ways of doing

When describing behaviours that indicate recovery, most comments were non-specific, related to *doing*

more, being more active or behaving as they had before:

'Well – I'm tempted to say they'd behave normally, but then what is normal? They undertake everyday activities without any difficulties.' (Male, age 59)

Behaviours involving interaction with other people, such as socialising more, being more talkative or getting 'out and about' were frequently described as indicating recovery:

'um, they would be more interactive, more social, less time lying about the place. Just the same things again; being active and social.' (Female, age 47)

Other specific 'ways of doing' mentioned by participants invoked a sense of personal agency in recovery, ranging from the physical aspects (eating better, crying less, changes in sleep patterns) to specific activities, particularly those enjoyed before depression:

'When I start to paint my toenails again. No seriously, when I can begin to feel music again and when I really long to play my cello.' (Female, age 41)

Ways of appearing

Some participants used observation to look for specific physical indicators of recovery, such as changes in facial expression, body language or 'demeanour':

'Well I think they would have a smile on their face, a twinkle in their eye.' (Female, age 57)

For others, recovery was decided by a two-step process of observation and interpretation, often with references to 'seeing' that someone was happier, less moody, brighter or less down:

'Oh, um, nature's a lot happier, judging by myself, don't seem to have that look on your face of worrying about things.' (Female, age 45)

Thus, the frequent comments describing happiness as an indicator of recovery were coded as a 'way of appearing' on the assumption that happiness (or absence of sadness) was commonly judged by a person's appearance. Nevertheless, it was not uncommon for participants to acknowledge the difficulty in relying solely on appearance as an indicator of recovery:

'I think it is a very difficult thing. Generally they would appear happier and have a happier aura and facial expressions and general level of activity and energy levels. And there again it may be in disguise. It is a very hard thing to know about.' (Male, age 48)

Ways of thinking and feeling

'You're able to talk about the things that have been really kept hidden within you; you wake up feeling like the day's going to be okay. And you start to like yourself as a person and accept the person that you are.' (Female, age 54)

A person's thoughts or feelings were the most common indicators of recovery overall, whether a person was answering for themselves or their assessment of others. This category was also the most difficult to categorise further, due to the non-specific terms used by participants. Most commonly, people spoke of a change in 'attitude' (especially words such as 'positive' and 'brighter') or change in 'outlook (on life)' or generally 'coping'.

'An easy-going attitude and can glide through life a little more clearly. That seems to be an indication.' (Female, age 36)

As with behaviours, there was a wide variety of specific thoughts or feelings mentioned, for example, feeling in control, feeling less anxious, feeling that one belonged or a change in understanding of self, as suggested by the following quote:

'Ummm ... I think they'd start to feel a growing security about themselves, they'd be feeling less dependent on others for things like approval or love. They'd become more independent but also more they wouldn't be isolating in that. They'd be happy to receive the good things that people have got for them but also they'd be able to start giving to themselves. Just be more accepting of themselves and knowing themselves a bit more.' (Male, age 28)

Discussion

This study presents the views of Australian primary care patients who have experienced symptoms of depression of all levels of severity. This makes the study somewhat unusual, as this large, random sample of patients is likely to be highly representative of the kinds of depressed people encountered in the day-to-day primary care setting. A limitation of our approach is that the analysis focused on only one question within a longer structured interview, trading in-depth analysis of a smaller number of interviews for a breadth of ideas about recovery. However, this has been useful in developing a broad picture of issues facing primary care patients when setting goals for recovery.

These patients offer a rich variety of views about what constitutes recovery and how it is detected. Participants' comments about the subjective nature

of depression and recovery are in keeping with Double's critique of the clinician's over-reliance on objective assessment.²⁰ Nonetheless, participants did describe how, via interaction and observation, they attempted to capture the behaviours, appearances, thoughts and feelings of an individual, which might assist them in deciding if recovery had occurred.

This emphasis on people's behaviour, thoughts and feelings as recovery indicators suggests a language of recovery that underemphasises the specific symptoms of depression described in ICD-10³⁶ and DSM IV.³⁷ Thus, the data are in keeping with the findings described by Zimmerman *et al*²⁷ and support the move in depression guidelines towards a more holistic view of recovery.¹¹

The possibility of detecting recovery by how a person appears is consistent with how clinicians have described recognising depression in patients they know.³⁸ However, this confidence seems to conflict with the view that people hide their depression. This raises questions about the utility of tools that primary care physicians might select to monitor depression outcomes, prompting the need for research that investigates ways of overcoming the obstacle of concealment.

This study challenges us to consider how patients can be engaged in the process of monitoring recovery from depression. Is the routine use of validated symptom scales the best approach? There is evidence emerging that symptom scales may be acceptable to patients as part of assessment of the severity of depression.³⁹ There is less information about how acceptable such tools would be if used repeatedly over time to monitor recovery, although evaluations from collaborative care trials for depression suggest that patients⁴⁰ and clinicians⁴¹ recognise the value of using these tools for monitoring. How should a clinician reconcile the convenience and utility of a tool that measures symptoms with the rich and complex accounts that define recovery in the data reported here?

Patients have expressed a preference for personal versus professional approaches in dealing with depression.⁴² Evidence also shows that people who report greater involvement in decision making have a higher probability of resolution of depression.⁴³ We feel this data adds further support for research into more patient-centred approaches to monitoring depression, that take into account the patient's views on recovery.⁴⁴

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ETHICAL APPROVAL

Granted by The University of Melbourne Health Sciences Human Ethics Sub-Committee.

CONFLICTS OF INTEREST

None.

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