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The Experience of Participation in Suicide Research from the Perspective of Individuals with Bipolar Disorder --Manuscript Draft--

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Abstract:	Reasons underlying the elevated prevalence of suicide in bipolar disorder remain under researched and poorly understood. Participation in suicide-focused research may pose a risk to vulnerable groups, such as those with bipolar disorder. Participants were asked to provide feedback about their experience of participating in a suicide-focused qualitative research interview. Data was analysed using inductive thematic analysis. Qualitative themes were, (1) talking about suicide was not distressing (2) negative interview expectations (3) personal benefits (4) value of suicide research (5) interview advice, and (6) talking about suicide was difficult. Suicide-focused research can be conducted with minimal participant distress. Sufficient procedures must be in place, both to identify those at risk of experiencing distress and to efficiently deal with any distress which might occur.
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Title: *The Experience of Participation in Suicide Research from the Perspective of Individuals with Bipolar Disorder*

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Abstract

Reasons underlying the elevated prevalence of suicide in bipolar disorder remain under researched and poorly understood. Participation in suicide-focused research may pose a risk to vulnerable groups, such as those with bipolar disorder. Participants were asked to provide feedback about their experience of participating in a suicide-focused qualitative research interview. Data was analysed using inductive thematic analysis. Qualitative themes were, (1) talking about suicide was not distressing (2) negative interview expectations (3) personal benefits (4) value of suicide research (5) interview advice, and (6) talking about suicide was difficult. Suicide-focused research can be conducted with minimal participant distress. Sufficient procedures must be in place, both to identify those at risk of experiencing distress and to efficiently deal with any distress which might occur.

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Introduction

People who experience bipolar disorder are at heightened risk of suicide (e.g., Clements et al., 2014; Rihmer & Kiss, 2002). A recent UK study reported that 114 people with bipolar disorder died by suicide each year between 1996 and 2009. A prospective follow-up study tracked 106 individuals with bipolar disorder for 38 years and documented that 7% of the sample completed suicide during this time (Angst, Stasson, Clayton & Angst, 2002). Yet the psychological mechanisms underlying suicide in people with bipolar disorder remain under researched and poorly understood (e.g., Mann et al., 2005; Umamaheswari, Avasthi, & Grover, 2014). The limited research in this area may be partly due to concerns about protecting vulnerable populations from possible harm caused by research participation (Edwards & McNamee, 2005; National Commission for the Protection of Human Subjects, 1979; Taylor et al., 2010). Concerns regarding the possible impact of participating in research are particularly relevant to studies investigating topics of a sensitive nature, such as suicide, in individuals who exhibit a heightened sensitivity to stress, including those with a clinically diagnosed mental health problem (Roberts, 2000; Wilson & Stanley, 2006). Despite these negative preconceptions, few studies have examined participants' subjective experiences of potentially distressing suicide research and none have investigated this from the point of view of individuals with bipolar disorder. Therefore, such preconceptions may be unsubstantiated and could unnecessarily prevent the successful completion of suicide-focused research in clinical populations. There is evidence that participants with more severe mental health problems have a lower threshold for experiencing distress during research, compared to the general population (e.g., Boothroyd, 2000). However, a systematic review of 46 studies which examined distress as a result of participating in psychiatric research found that only a minority of participants (less than 10%) experienced distress (Jorm, Kelly & Morgan, 2007). The overarching aim of the current study was to explore the subjective experience of participating in a suicide-focused qualitative research interview, from the perspective of individuals with a diagnosis of bipolar disorder.

Method

Procedure

Potential participants underwent a brief telephone screening interview administered by the first author (RO) to assess the likelihood of a bipolar disorder diagnosis. Individuals who had a positive screen (a score of seven or above) on the Mood Disorders Questionnaire (Hirschfield, 2002) took part in a full structured clinical interview, using the Structured Clinical Interview for DSM-IV Axis I Disorders, Research Version (SCID; First, Gibbon, Spitzer, Williams & Benjamin, 1997).

Once a diagnosis of Bipolar Disorder I or II was confirmed (First et al., 1997), participants were invited to take part in the suicide-focused qualitative interview. Participants were asked to provide oral feedback regarding their experience of taking part in the suicide-focused research interview. This feedback data was analysed as part of the current study.

Participants

Twenty participants were recruited based upon the following inclusion criteria:

1. A primary diagnosis of bipolar disorder (I or II) according to the SCID (First et al., 1997).
2. Past experience of suicidal thoughts, feelings and/or behaviours.
3. In regular contact with a care-coordinator or an equivalent named health professional.
4. Aged 18-65 years.
5. Sufficient English language skills to take part in the interview.

Recruitment

The study was approved by the NHS Research Ethics Committee (Ref: 13/NW/0846). Participants were recruited across the North West of England, in collaboration with a range of NHS and non-NHS services, including, community mental health teams, primary care services and support groups, such as, Bipolar UK. Participants could also self-refer into the study in response to flyers and posters placed in areas accessed by potential participants (e.g., community centres). Advertisements were placed in local newspapers and online social media. Advertising materials informed potential participants that the study would involve a 'confidential interview about bipolar experiences and suicidal feelings'. If an individual wished to obtain further information, they were able to contact the first author directly by phone or email. All participants were euthymic when they took part in the qualitative interview, i.e., they did not meet criteria for a clinically significant mood episode (depression/mania/hypomania) according to the SCID.

This data represents the analysis of a feedback question following an interview designed to investigate participants' perceptions of which factors they deemed important in the development of suicidal thoughts (Owen, Gooding, Dempsey & Jones, 2015). Thematic saturation for this data was reached once 20 participants had been interviewed hence recruitment was closed at this point

Measures

The Mood Disorder Questionnaire (MDQ; Hirschfeld, 2002)

The MDQ consists of 13 questions regarding symptoms of bipolar disorder (e.g., "Has there ever been a period of time when you were not your usual self and thoughts raced around your head or you couldn't slow your mind down?"). Participants indicate whether they had ever experienced these symptoms (yes/no). A score of seven or above signifies that a bipolar disorder diagnosis is probable (Hirschfeld, 2002). The MDQ has demonstrated good sensitivity (0.281) and excellent specificity (0.972) (Hirschfeld et al., 2003).

The Structured Clinical Interview for DSM-IV Axis I Disorders, Research Version (SCID; First et al., 1997)

This is a structured interview for assessing whether an individual meets full criteria for the Major DSM-IV Axis I disorders. It remains the gold standard for confirming psychiatric diagnoses in clinical trials (First et al., 1997; Lobbestael, Leurgans & Arntz, 2011). Modules A (Mood Episodes), B

(Psychotic and Associated Symptoms), C (Psychotic Disorders), D (Mood Disorders), E (Substance Use Disorders) and F (Anxiety Disorders) were administered. The researcher administering the measures (RO) was fully trained and experienced. Training for the SCID tool involved an intensive period of watching instructional DVDs, studying the training manual, role plays with service users who had lived experience of bipolar disorder and shadowing experienced research assistants whilst they administered the SCID. RO had previously gained two years' experience administering clinical and qualitative interviews during her work as a research assistant. RO also attended ongoing regular weekly one-to-one supervision and monthly group supervision.

The Semi-Structured Suicide-Focused Qualitative Interview

The interview topic guide was developed following a review of the relevant research literature, discussion within the research team and consultation with a service-user advisory panel. Questions were designed to elicit participants' past experiences of suicidal thoughts, feelings, and behaviours. Following each interview, participants were asked for feedback regarding their experience of taking part in suicide research. This involved posing the question, "some people can find talking about suicide difficult, whereas other people can find it useful; how did you find talking part in suicide research?"

Qualitative Analysis

Participant responses to the feedback question were analysed using an inductive thematic analysis (Braun & Clarke, 2006). This allowed the identification of key themes or topics which were repeated across participant responses. A coding manual was developed according to the identification of common experiences communicated across the data (the first author can be contacted for a copy of the coding manual). The research team reached consensus regarding each theme and agreed that the themes were representative of the data. Thematic analysis was used as a realist method which allowed experiences of participants to be presented as they were reported.

Results

Participants

The mean age of participants was 45.6 (range 26-60). All met criteria for bipolar disorder according to the SCID. There was a considerable range in terms of frequencies of mood episodes, with 0-200 depressive episodes (mean = 27), and 2-50 manic or hypomanic episodes (mean = 16) reported. Participants' self-reported past experience of suicidality also varied considerably, with 1-100 experiences of suicidal thoughts (mean = 24), 0-50 suicide plans made (mean = 6), and 0-13 suicide attempts (mean = 3). Table 1 shows the key participant characteristics.

Table 1. Demographic and clinical characteristics of participants.

Thematic Analysis

Themes relating to interview feedback were grouped into, (1) talking about suicide was not distressing, (2) negative interview expectations, (3) personal benefits, (4) the value of suicide research, (5) interview advice, (6) talking about suicide was difficult.

Talking about Suicide was Not Distressing

The majority of participants (17 /20) did not find talking about suicide to be distressing.

P19: *“I’m okay, I didn’t find it distressing, I didn’t find it unsettling or upsetting, I thought it was fine”*.

Participants praised the interview for being thought-provoking without having induced low mood.

P10: *“It makes people think and it makes people think in a way that won’t leave them feeling, you know, really down”*.

Negative Interview Expectations

Despite not finding the interview distressing, 11 participants disclosed that they had prior negative expectations regarding how they would cope with talking about suicide-related experiences.

P11: *“I mean obviously that first week I was supposed to come and see you I made up an excuse and didn’t turn up, I was just scared, is scared the right word? Or more like apprehensive”*.

Those who were apprehensive reported that their negative expectations were not comparable to their actual interview experience.

P5: *“I was dreading it really but it’s not been as hard as I thought”*.

Four participants indicated that their negative expectations were because they had not talked about suicide in depth before. For two individuals, the interview was the first time they had disclosed to another person that they had felt suicidal.

P18: *“This is probably the first time I’ve chatted about suicidal feelings, I don’t think anyone’s ever asked me”*.

Participants who did *not* have prior concerns about the interview (N=9) were typically those who had frequent experience talking about suicidal thoughts and feelings with health professionals.

P2: *“I’ve answered so many questions on it I’ve become quite detached from it”*.

Personal Benefits

Nine participants informed us that they had gained personal benefits as a result of taking part in the interviews. This included developing a better awareness and understanding of their experiences.

P20: *“I found it quite therapeutic actually and again it’s helping me make sense of things by talking about it”*.

The enhanced awareness they achieved as a result of taking part in the interview translated into two participants asking for extra mental health support.

P4: *“Actually, talking to you about how I was feeling in the last interview made me realise that I was feeling a bit down, so I’ve been in touch with my nurse”.*

Six participants associated taking part in the research with making progress in terms of their own personal recovery.

P3: *“You have given me an opportunity that I’ve been waiting for, for over a year, it’s been yet another step on that ladder, but it’s a big one”.*

Participants who had not talked about suicide in-depth before suggested that the experience may make it easier to disclose such feelings should they occur again in the future.

P11: *“I suppose now I’ve sat there and again, once I’ve chatted to someone about it like I have now, maybe it will make it easier to talk to someone if it happens again”.*

The Value of Suicide Research

Most participants (15/20) reported that they viewed the research as valuable and worthwhile.

P10: *“You need to really really carry on with this study, it’s been really informative and you’ll do a lot of good if you carry on with it, because a lot of people don’t understand”.*

Participants often disclosed that their reason for taking part in the study was the desire to help others.

P4: *“I’m happy that I’m helping the research, it’s good to know I’m using my illness for something useful that will help other people”.*

Interview Advice

Thirteen participants gave advice regarding future suicide-focused research interviews. Advice included ensuring mood stability at the time of the interview.

P5: *“I think because I’m stable, I’ve got that distance between me now, and between me at my last attempt, and the fact that my life has changed so beyond recognition, I can talk about it now, not dispassionately, but with a sense of perspective”.*

Traits of the researcher were cited as being important in making participants feel at ease.

P17: *“Being honest I think because you’ve got a very sort of personable laid back approach and I think that puts people at ease to be honest, you know”.*

Building up to talking about suicide gradually also helped participants to feel comfortable.

P11: *“I think doing last week’s interview about my mood first was a good idea, I don’t think I could have done it otherwise, which is probably why I didn’t turn up last week because I thought it was gonna be straight in at the deep end, so yeah, no it’s been ok”.*

Finally, the opportunity to take breaks was viewed as crucial to minimising distress.

P14: *“Giving people the chance to take a break I think is really important, because it can be really distressing for some people”.*

Talking about Suicide was Difficult

It is important to note that a small number of participants (three/20) disclosed that they found talking about suicide difficult.

P12: *“I mean some of it reminds you of the bad times and you don’t always want to go back to those dark places”.*

Two participants who found the interview difficult explained that this was because they were in difficult life circumstances at the time of the interview. One participant had full-time caring responsibilities for a disabled parent, and the other was involved in an ongoing court dispute with family members which had potential adverse financial consequences.

P9: *“I found it hard because I’m feeling quite low at the minute, I don’t know how I keep having the strength when she’s shouting at me and criticising me”.*

P16: *“It was difficult, because it brings ideas to your head, just talking about it to somebody else, because I’ve still got this thing hanging over me”.*

Discussion

The aim of the present study was to investigate the subjective experience of participation in suicide research from the perspective of individuals with a bipolar disorder diagnosis. Qualitative themes were grouped into: (1) talking about suicide was not distressing; (2) negative interview expectations; (3) personal benefits; (4) the value of suicide research; (5) interview advice; (6) talking about suicide was difficult.

Five of 20 participants had a diagnosis of bipolar II disorder, whilst the remaining participants were all diagnosed with bipolar I disorder. Individuals with both diagnoses contributed to each theme which suggests that perhaps the type of bipolar diagnosis does not influence experiences of participation in suicide research. Furthermore, the individuals who were diagnosed as bipolar II (particularly the younger participants, e.g., participant 2 – aged 26; participant 10 – aged 27) may indeed become bipolar I over time. Thus, the apparent distinction is not clear cut.

The majority of participants (17 out of 20) reported that taking part in suicide research was not distressing. This is consistent with findings from previous research in which individuals were asked about sensitive personal topics, such as, trauma and palliative care (Griffin, Resick, Waldrop & Mechanic, 2003; Hudson, 2003). In addition, one study elicited feedback from participants with a diagnosis of schizophrenia about their involvement in suicide-focused research (Taylor et al., 2010). This study reported positive experiences, including feelings of altruism and catharsis (Taylor et al., 2010). The current study suggests similar benefits for those with bipolar disorder.

Personal benefits of taking part in the current study included developing a better awareness and understanding of suicide-related experiences, and gaining emotional support. This echoes other reports concerning the positive effects of participation in mental health research, for instance, educational gains, and empowerment (Dyregrov, 2004; Hawton et al., 1998; McLoud, 1994; Riches & Dawson, 1996; Taylor et al., 2010).

Participants’ negative interview expectations often depended on the extent to which participants had previously talked about suicide-related experiences with health professionals. Those who had frequently talked about suicidal feelings with professionals reported a sense of detachment

and, therefore, did not expect to become upset. Conversely, those with no such experiences were more apprehensive. Consistent with work examining schizophrenia (Taylor et al., 2010), the researcher in the current study alleviated participants' anxieties by thoroughly explaining the study procedure, addressing concerns, and engaging participants in a detailed and interactive de-briefing post-interview.

Only a small percentage of participants found that recalling their past suicidal feelings was difficult. Reasons for this were: (1) lack of disclosure prior to the interview; (2) low mood; (3) current difficult and entrapping life situations. Although it is difficult to predict exactly who will become distressed upon discussion of a sensitive topic, assessing the presence of the above factors may help to ascertain whether or not an individual will find talking about suicide distressing.

There is arguably a tendency for research ethics committees to be over-cautious regarding the negative effects of participation in suicide-focused research. They perhaps believe that it is better not to broach the subject of suicide in research studies, because it might trigger suicidal thoughts that were not otherwise present. Similarly, trainee clinicians can be apprehensive of probing a patient's experiences of suicidal ideation as they are unclear of the appropriate course of action to take and are consequently reluctant to push the boundaries of risk. However, evidence from the current study indicates that talking about suicidal feelings does *not* cause or amplify suicidal thoughts and behaviours. Clearly, there is an ongoing educational challenge to raise awareness about this issue.

Clinical Guidelines

Distress management procedures must be flexible enough to manage potential variation in the nature and level of distress experienced by each participant. Based upon the findings from the present study, the research team present the following clinical guidelines which may be useful for minimising participant distress: (1) researchers should ensure that clear and thorough informed consent procedures are adhered to beforehand, to help give a realistic insight into what the study will entail; (2) the researcher conducting the assessments should have extensive training in clinical interviewing and discussing topics of a sensitive nature; (3) the researcher should ensure that participants' mood is sufficiently stable and they are not at imminent risk of suicide. The researcher should take both mood stability and the participant's individual life circumstances into consideration when making this judgement; (4) participants should be offered the opportunity to take regular breaks throughout the duration of the study; (5) researchers should liaise with the participants' care team when any risk issues arise to ensure a timely and effective mechanism for reporting distress; (6) participants should also be given access to out-of-hours 24 hour support helplines, such as, the Samaritans.

The research team also suggest that research studies investigating suicidality should include the following guidelines as good practice: (1) a reflexive de-briefing should take place after each interview, in which participants are encouraged to provide feedback about their experiences and voice any concerns; (2) participants should be offered the opportunity to take part in a brief positive mood induction exercise at the end of each interview; (3) a follow-up phone-call should be offered to all

participants the day after the interview is conducted, in order to check whether any participant may be experiencing prolonged distress as a result of the interview.

As the interview in the current study was for research purposes, we felt that it was ethically important to ensure that participants were euthymic and not experiencing current suicidal ideation. We acknowledge that in clinical settings where it is necessary to measure immediate suicide risk, this is not always possible. As such, it cannot be ruled out that participants who are currently suicidal may find the completion of suicide assessments and interviews distressing.

In principle, clinical and research assessments of suicide are similar in that they both aim to identify suicide risk by measuring the presence of factors which may facilitate the development of suicidal thoughts and behaviours. Clinical realities, however, can often necessitate compromise and lead to differences both in how the assessments are carried out and how the client responds to the assessments.

Strengths and Limitations

A key strength of the current study was that feedback about the subjective experience of participation was provided shortly after the end of the suicide focused interview. This timely data collection ensured that the accuracy of participant responses was maximised and responses were not affected by memory biases. However, this was also a limitation, as the timely data collection did not give participants the opportunity to reflect on their experience of taking part in the study. Perhaps if the three participants who found it distressing were given some time to reflect, they may have reported a different view after one or two days.

A further limitation was that participants may have been reluctant to disclose negative feedback regarding their experiences, particularly as they were asked to provide oral feedback directly to the researcher. Written feedback would have been an alternative option. However, this can elicit responses which are too brief (Taylor et al., 2010). The semi-structured interview adopted by the current study allowed participants to express their views more effectively and with fewer constraints.

Conclusion

To conclude, the current study demonstrated that individuals with bipolar disorder largely reported that talking about suicide as part of a research study was not a distressing experience, and, indeed, had a number of positive consequences. However, three participants did find talking about suicide-related experiences to be difficult. This suggests that suicide-focused interviews and assessments can be conducted with minimal participant distress, but that adequate procedures must be in place both to identify those participants who are at a higher risk of becoming distressed and to effectively deal with any distress which may occur as a result of discussing suicide-related experiences.

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