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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 underresearched 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. The data set was analyzed 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 that might occur.

Key Words: Bipolar disorder, involvement, participation, research ethics, suicide (*J Nerv Ment Dis* 2016;00: 00–00)

People who experience bipolar disorder are at heightened risk of suicide (eg, see Clements et al., 2013; Rihmer and 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 et al., 2002). Yet the psychological mechanisms underlying suicide in people with bipolar disorder remain underresearched and poorly understood (eg, see Mann et al., 2005; Umamaheswari et al., 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 and 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 et al., 2000; Wilson and Stanely, 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 with the general population (eg, Boothroyd, 2000). However, a systematic review of 46 studies that examined distress as a

result of participating in psychiatric research found that only a minority of participants (<10%) experienced distress (Jorm et al., 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.

METHODS

Procedure

Potential participants underwent a brief telephone screening interview administered by the first author (R.O.) to assess the likelihood of a bipolar disorder diagnosis. Individuals who had a positive screen (a score of ≥ 7) on the Mood Disorders Questionnaire (Hirschfeld et al., 2000) took part in a face-to-face structured clinical interview, using the Structured Clinical Interview for *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)* Axis I Disorders (SCID), Research Version (First et al., 1997). This was to confirm that participants had a diagnosis of bipolar disorder for research purposes.

Once a diagnosis of bipolar disorder I or II was confirmed (First et al., 1997), participants were given a separate appointment and 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. These feedback data were analyzed as part of the current study.

Participants

Twenty participants were recruited based on the following inclusion criteria:

1. A primary diagnosis of bipolar disorder (I or II) according to the SCID (First et al., 1997);
2. experience of suicidal thoughts, feelings, and/or behaviors, assessed via the SCID;
3. in regular contact with a care coordinator or an equivalent-named health professional;
4. aged 18 to 65 years; and
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 (eg, community centers). 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 e-mail. All participants were euthymic when they took part in the qualitative interview; that is, they did not meet criteria for a clinically significant mood episode (depression/mania/hypomania) according to the SCID.

These data represent the analysis of a feedback question following an interview designed to investigate participants' perceptions of

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which factors they deemed important in the development of suicidal thoughts (Owen et al., 2015). Thematic saturation for these data were reached once 20 participants had been interviewed; hence, recruitment was closed at this point.

Measures

The Mood Disorder Questionnaire

The Mood Disorder Questionnaire consists of 13 questions regarding symptoms of bipolar disorder (eg, “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?”) (Hirschfeld et al., 2000). Participants indicate whether they had ever experienced these symptoms (yes/no). A score of 7 or greater signifies that a bipolar disorder diagnosis is probable (Hirschfeld et al., 2000). The Mood Disorder Questionnaire has demonstrated good sensitivity (0.281) and excellent specificity (0.972) (Hirschfeld et al., 2000).

The SCID, Research Version

This is a structured interview for assessing whether an individual meets full criteria for the major *DSM-IV* Axis I disorders (First et al., 1997). It remains the criterion standard for confirming psychiatric diagnoses in clinical trials (First et al., 1997; Lobbetael et al., 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 (R.O.) was fully trained and experienced. Training for the SCID tool involved an intensive period of watching instructional DVDs, studying the training manual, role playing with service users who had lived experience of bipolar disorder, and shadowing experienced research assistants while they administered the SCID. R.O. had previously gained 2 years’ experience administering clinical and qualitative interviews during her work as a research assistant. R.O. also attended ongoing regular weekly one-to-one supervision and monthly group supervision.

The Semistructured Suicide-Focused Qualitative Interview

All qualitative interviews were conducted one-to-one with the first author and the participant, either at the participant’s home or on university premises. 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’ experiences of suicidal thoughts, feelings, and behaviors. The interview topic guide elicited (i) an in-depth description of how it felt to be suicidal, (ii) participants’ perceptions of factors that triggered the development of suicidal thoughts and behaviors, (iii) perceptions of factors that protected against suicidal thoughts and behaviors or helped participants when they felt suicidal, and (iv) how symptoms of bipolar disorder affected feelings of suicide.

Although there were a number of core questions that were asked of every participant (eg, “Have you ever experienced thoughts or feelings of wanting to kill yourself?”), the qualitative interview was semistructured and flexible enough to incorporate individual experiences that had perhaps not been anticipated in the original interview outline. Each interview lasted between 35 and 90 minutes. Interviews were audio recorded (with participant consent) to facilitate transcription and data analysis.

Following each interview, participants were asked for feedback regarding their experience of taking part in suicide research. This involved posing a single open-ended question, which was: “Some people can find talking about suicide difficult, whereas other people can find it useful; how did you find taking part in suicide research?” Participants were then allowed to speak freely for as long as they wished regarding their experience of taking part in the interview.

Qualitative Data Analysis

Participant responses to the feedback question were analyzed using an inductive thematic analysis (Braun and Clarke, 2006). Thematic analysis was used as a realist method that allowed experiences of participants to be presented as they were reported.

The first author transcribed all audio recordings. An initial coding system was developed by grouping together similar feedback and labeling them under a common subheading that summarized the nature of the feedback. The coding system was then applied to the data, and similar codes were grouped together to form initial themes. Initial themes were presented to the wider academic and clinical team for discussion, during which theme content and provisional theme labels were agreed upon. Twenty-five percent of transcripts were circulated among the research team who were asked to apply the coding system to the data in order to establish reliability. The research team reached consensus regarding each theme and agreed that the themes were representative of the data. Once new themes ceased to emerge, this indicated that thematic saturation had been reached.

RESULTS

Participants

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

Thematic Analysis

Themes relating to interview feedback were grouped into (1) talking about suicide was not distressing, (2) negative interview

TABLE 1. Sociodemographic Information

Participant	Age at Interview, y	Sex	Marital Status	Education	Employed
1	39	Male	Single	Higher	Voluntary
2	26	Female	Partnered	Postgraduate	Full time
3	60	Male	Married	GCSEs	Retired
4	44	Female	Partnered	Postgraduate	Full time
5	38	Female	Married	Postgraduate	Full time
6	45	Female	Married	Further	Unemployed
7	49	Female	Single	Further	Unemployed
8	41	Male	Single	Higher	Voluntary
9	51	Female	Single	GCSEs	Unemployed
10	27	Female	Partnered	Higher	Unemployed
11	45	Male	Single	Higher	Unemployed
12	55	Female	Married	GCSEs	Unemployed
13	59	Male	Single	Higher	Unemployed
14	53	Female	Partnered	Further	Unemployed
15	57	Female	Married	GCSEs	Part time
16	51	Female	Single	GCSEs	Unemployed
17	34	Female	Partnered	Postgraduate	Unemployed
18	50	Male	Partnered	GCSEs	Unemployed
19	48	Male	Single	Further	Self-employed
20	43	Female	Single	Postgraduate	Part time

GCSEs indicates General Certificate of Secondary Education.

expectations, (3) personal benefits, (4) the value of suicide research, (5) interview advice, and (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 2 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 2 participants asking for extra mental health support:

P4: Actually, talking to you about how I was feeling in the last interview made me realize 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 minimizing 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 (3/20) 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 criticizing 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, and (6) talking about suicide was difficult.

Five of 20 participants had a diagnosis of bipolar II disorder, whereas the remaining 15 participants all received a diagnosis of 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 received a diagnosis of bipolar II (particularly the younger participants, eg, participant 2 [aged 26 years], participant 10 [aged 27 years]) may indeed become bipolar I over time. Thus, the apparent distinction is not clear cut.

The majority of participants (17/20) 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 et al., 2003; Hudson, 2003). In addition, 1 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.

The severity of participants' experiences of suicidality varied substantially. Some participants had experienced only fleeting suicidal thoughts during their lifetime, whereas others had carried out multiple highly lethal suicide attempts. However, the vast majority of participants, irrespective of their suicide history severity, reported that taking part in suicide research was a positive experience. This suggests that distress experienced during research participation may not necessarily be moderated by the severity of past suicidality.

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 and 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 debriefing postinterview.

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, and (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 an individual will find talking about suicide distressing.

There is arguably a tendency for research ethics committees to be overcautious 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 behaviors. 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 on the findings from the present study, the research team present the following clinical guidelines, which may be useful for minimizing 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 judgment; (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 suggests that research studies investigating suicidality should include the following guidelines as good practice: (1) a reflexive debriefing 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; and (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 behaviors. 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 maximized, 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 3 participants who found it distressing were given some time to reflect, they may have reported a different view after 1 or 2 days. Equally, participants who did *not* find it distressing at the time may have reflected on the experience after a number of days and evaluated it as more distressing.

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 that are too brief (Taylor et al., 2010). An alternative strategy would have been to allow participants to provide feedback to a different research assistant or to record their feedback on the Dictaphone without the presence of any researchers for later transcription and coding.

CONCLUSIONS

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, 3 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 that may occur as a result of discussing suicide-related experiences.

DISCLOSURE

The authors declare no conflicts of interest.

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