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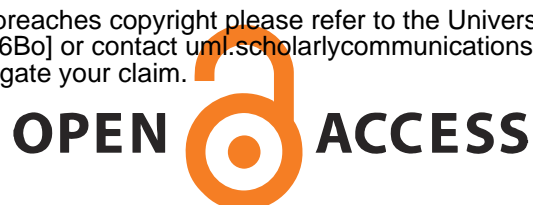
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A systematic investigation of the short and long term experiences of taking part in research about suicidal thoughts and acts in the context of a randomised controlled trial



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ABSTRACT

Partaking in studies about suicide can be a positive experience. There is also evidence of some negative impacts in the days immediately following participation. No research has examined both the short and longer term effects of repeated assessment of an individual's suicidal thoughts/behaviours. Clinical trials can involve multiple suicide assessments over several months. The current study investigated whether participants experienced any brief or lasting effects from this kind of intense suicide focused research. Participants had recent suicidal experiences, and were participating in a randomised controlled trial evaluating a psychological therapy targeting suicidal experiences for people with non-affective psychosis. Multiple measures of suicidal thoughts/acts were completed at baseline, 6 and 12-month follow-up time-periods. For the current study, participants (N = 100 at baseline and n = 32 at follow-up) undertook a semi-structured qualitative interview about their experiences of taking part in suicide research, and completed a checklist of adjectives to describe how it felt to talk about suicide during the assessments. They rated their current mood before and after completing the trial assessments using a visual analogue scale. A convergent mixed methods approach indicated that participation was positive in both the short and longer term. Mood improved or did not change over the course of assessments. More positive than negative adjectives were selected, regardless of the severity of suicidal thoughts experienced by participants. Thematic analysis of the qualitative data revealed many benefits of participating, including catharsis, being able to help others and being part of a wider endeavour to understand suicidal experiences. Both short and longer term feelings of distress arising from participation were offset by the expectation and acceptance of this occurring, together with the application of participant-initiated coping strategies. These findings lend reassurance that inviting people with severe mental health problems to participate in suicide research is not detrimental in either the short or long-term.

1. Introduction

Globally, suicide is a leading cause of death (World Health Organisation [WHO], 2019). Much research has focused on investigating epidemiological and psychological 'risk' factors associated with suicidal experiences (Platt et al., 2019). However, researching suicidal experiences can be ethically challenging (Biddle et al., 2013). There are concerns that asking people about their suicidal experiences may trigger

and/or amplify these thoughts and/or behaviours (e.g., Bajaj et al., 2008; Blades et al., 2018; Awenat et al., 2017). For example, in a survey of 62 international suicide researchers, 40% reported that ethics committees had cautioned about the potential for distress or increased suicidal ideation for participants (Andriessen et al., 2019b). Indeed, 65% of respondents of an international survey of 125 ethics committee members disclosed concerns that talking about suicidal experiences could exacerbate suicidal thoughts/acts (Lakeman and Fitzgerald, 2009). Clearly,

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evidence is needed to address these concerns.

A review concluded there was no evidence of harm for participants partaking in psychiatric research, though there was limited evidence about longer-term effects (Jorm et al., 2007). It is only relatively recently that researchers have begun to examine participants' experiences of taking part in research about suicide. Negative, positive, and mixed effects have been identified (Biddle et al., 2013; Blades et al., 2018; Hawton et al., 2003; Littlewood et al., 2019; Owen et al., 2016; Taylor et al., 2010b). Negative impacts have included low mood (Taylor et al., 2010b), distress associated with recalling a traumatic event (e.g., a near fatal suicide attempt; Biddle et al., 2013), and anxiety and uncertainty around what taking part might involve (Taylor et al., 2010b). Some evidence suggests that negative effects were anticipated to be short term by participants who balanced this potential detrimental impact with a desire to contribute to research into suicide (Biddle et al., 2013). Both Hawton et al. (2003) and Littlewood et al. (2019) found that a lowering of mood after participating was short lived with a return to usual mood within a day. Similarly, Gould et al. (2005) and Bender (2012) concluded that participating in suicide research had no negative effects over a two-day time window.

Positive effects from participating in suicide research have also been documented (Biddle et al., 2013; Blades et al., 2018; Owen et al., 2016) and may persist (Littlewood et al., 2019). Examples include catharsis (Littlewood et al., 2019; Taylor et al., 2010b); reflection and/or increased self-understanding (Biddle et al., 2013; Gibson et al., 2014; Littlewood et al., 2019); and a reduction in both suicidal ideation and behaviours (Blades et al., 2018). Importantly, positive experiences have been documented as co-occurring alongside negative experiences. For example, altruism and personal therapeutic gain (e.g., increased awareness) were experienced in conjunction with distress arising from disclosure (Taylor et al., 2010b).

Research into the longer-term impact of participation in suicide research in adults is sparse, revealing a clear gap in the literature (Jorm et al., 2007). Littlewood et al. (2019) followed up, between one and 13 months later, a small sample of adults ($n = 23$) who had taken part in a qualitative interview about their suicidal thoughts/acts. Participants reported positive experiences, including catharsis, personal benefits and benefits to others. Negative experiences were also disclosed, such as feelings of shame or embarrassment, distress from talking about suicidal thoughts/behaviours, and a short-lived lowering of mood, but these sat alongside the positive benefits of taking part.

To date researchers have primarily focused on the impact of taking part using cross-sectional designs. Randomised controlled trials (RCTs) investigating suicidal thoughts/acts usually involve the completion of a number of suicide and related questionnaire measures (e.g., suicidal thoughts/plans/acts, depression, hopelessness, defeat, entrapment) and, sometimes, structured clinical interviews, across multiple time points (Gooding et al., 2020; Haddock et al., 2019; Pratt et al., 2015; Tarrier et al., 2013). The experience of taking part in such trials may have an intensity not otherwise experienced in suicide studies which are not RCTs.

RCTs also present an opportunity to examine a third gap in the field, which is to investigate the extent to which the severity of suicidal thoughts/behaviours affect the experience of taking part in research on this topic. Only one study has investigated this type of repeated suicide assessments. Reynolds et al. (2006) measured changes in distress and suicidality amongst individuals who had completed questionnaires over a two-year period. They concluded that longer term changes were rare, and as likely to reflect decreases as increases in distress. However, their quantitative study did not qualitatively explore the experience of taking part in these assessments.

Accordingly, three research questions were examined in the current study in a context of a suicide focused RCT with people who had received a diagnosis of non-affective psychosis (Cognitive AppRoaches to coMbatting Suicidality [CARMS] Gooding et al., 2020) which were: i) What is the experience of participating in assessments during an RCT

investigating suicidal thoughts/behaviours? ii) What are the short and long-term effects of participation in this type of suicide research? iii) Does severity of suicidal thoughts affect the experience of taking part in suicide-related assessments? Focusing on this population is important as people with experiences of psychosis are at a higher risk of suicide thoughts and behaviours (Hor et al., 2010). If there are negative consequences of taking part in research about suicide this is a group who may be particularly vulnerable.

2. Methods

2.1. Patient and public involvement and engagement (PPIE)

People who were Experts-By-Experience with respect to both suicidal thoughts/behaviours and psychosis were involved in the design and conduct of CARMS (Gooding et al., 2020). As such, they contributed to the design, execution, interpretation and implications of the current study.

2.2. Study design

The design was mixed qualitative and quantitative methods. There were data collection time-points of baseline ($N = 100$), and 6 and 12-month follow-up during the trial. There was relatively high attrition at follow-ups and timings of the follow-up appointments varied. Consequently, for the purposes of the current study, quantitative data were included for the most recent follow-up appointment for any individual, and any qualitative follow-up data were included in the follow-up data corpus. Thirty-two participants are included in the follow-up dataset.

2.3. Sampling strategy

Participants were recruited from two arms of an RCT comprising suicide focused psychological therapy plus treatment as usual [TAU] versus TAU alone (Gooding et al., 2020). In both arms of the trial, participants completed assessments (to establish eligibility) and completed a range of questionnaires at multiple time points, which asked suicide behaviours and ideation, mood and related concepts such as feelings of defeat, hopelessness and entrapment. Participants had non-affective psychosis and had suicidal experiences in the three months prior to recruitment (see Gooding et al., 2020 for the inclusion and exclusion criteria and full list of measures/assessment timings).

Data analysis for short-term effects of contributing was based on the first 100 participants who consented to take part in the current study. Longitudinal data were only collected from participants in the 'treatment as usual' arm due to the possible influence of therapy on the experience of participating in the suicide assessments.

2.4. Data generation

Four data generation techniques were employed:

1. Qualitative semi-structured interviews

A topic guide was developed from the relevant literature and discussions with Experts-by-Experience. It explored participants' experiences of taking part in the suicide assessments.

2. The Adult Suicidal Ideation Questionnaire (ASIQ; Reynolds, 1991)

The ASIQ has 25 items with a 7 point scale ranging from '0 - I have never had this thought' to '6 - [I have had this thought] Almost every day'. Suicidal ideation is assessed over the past month. It appears psychometrically robust (Batterham et al., 2015). Cronbach's alpha in the current sample was 0.95.

3. Visual Analogue Scale (VAS) for mood (Yeung and Wong, 2019) The VAS is a brief quick, self-report mood measure of emotional valence using a pictorial scale of 0 (worst mood) to 100 (best mood).
4. Adjective checklist

Sixteen adjectives, eight positive (enjoyable, interesting, insightful, therapeutic, relaxing, worthwhile, calming and useful) and eight negative (upsetting, saddening, stressful, tiring, worrying, uncomfortable, embarrassing and anxiety provoking) were identified from apposite published studies (Biddle et al., 2013; Hawton et al., 2003; Owen et al., 2016; Taylor et al., 2010b). These adjectives formed a randomly ordered adjective checklist. Responses were binary (Yes/No).

2.5. Procedure

At each of the time-points after completing the RCT assessments (including the ASIQ), participants were invited by researchers to take part in the semi-structured qualitative interview and to complete the adjective checklist task. The VAS mood measure was completed at the beginning and end of each assessment session.

2.6. Data analysis

2.6.1. Qualitative analysis

Interviews were analysed using a hybrid deductive and inductive thematic approach, which allowed for the application of an analytical framework to the data corpus yet also offered scope for 'bottom-up' data driven codes to be generated (Braun and Clarke, 2019; Fereday and Muir-Cochrane, 2006). LC and SP refined the codes and final thematic structure. The wider research team met regularly to discuss the emerging analysis. NVivo version 11 was used to manage the analyses. The development of the final coding involved three phases:

Phase 1. There were three processes of i. Familiarisation, ii. Inductive line-by-line coding, and iii. Inductive coding a second time including reviewing, expanding and adapting initial codes.

Phase 2. Repeated or similar codes were merged and refined into broad patterns/categories using an inductive approach. Following this, a deductive framework was applied (Littlewood et al., 2019). Inductively coded data were organised, where possible, into the codes defined by the framework.

Phase 3. The framework was adapted and refined iteratively to account for salient new codes which were in addition to those demarcated in the framework (see Table 2).

2.6.2. Quantitative analysis

Data could not be combined across time-points because each data point needed to be independent. A specific mood change score was calculated for each assessment by subtracting the post-assessment scores from the pre-assessment scores. Analyses were non-parametric as appropriate and as detailed. SPSS version 25 (IBM Corp. Released, 2017) was used.

3. Results

3.1. Participant characteristics

One hundred people took part in baseline assessments and 32 at a follow-up (see Table 1). All were in contact with UK mental health services. Most participants were white, not currently employed, lived with others, and had received an ICD-10 diagnosis of a non-affective psychosis. There were marginally more men than women in the sample.

3.2. Research question 1: what was the experience of participating in assessments during an RCT investigating suicidal experiences?

Both qualitative interview data and quantitative data (VAS mood

Table 1

Demographic information for baseline (n = 100) and follow-up participants (n = 32) including ICD-10 code diagnostic information.

Age (years)	Baseline		Follow-up	
	Mn = 34 (range = 18–66)		Mn = 34 (range = 18–60)	
	n	%	n	%
Gender				
Male	55	55	17	53
Female	45	45	15	47
Ethnicity				
White	88	88	27	87
Black	4	4	0	0
Asian	4	4	2	6
Mixed Race	3	3	2	6
ICD- code Diagnosis				
F20 – Schizophrenia	72	72	25	78
F25 – Schizoaffective disorder	17	17	6	19
Other – F29, F22, F28, F22 or F23	11	11	1	3
Living situation				
Living with friends or family	65	65	23	72
Living alone	35	35	9	28
Employment				
Exempt	51	51	18	56
Unemployed	25	25	9	28
Part time	7	7	3	9
Full time	2	2	0	0
Voluntary work	5	5	2	6
Retired	5	5	0	0
Student	4	4	0	0
Homemaker	1	1	0	0
Allocation				
TAU	51	51	32	100
Therapy + TAU	49	49	–	–

scores and adjective checklist selection responses) were used to address the first research question.

3.3. Qualitative data

Five key themes applied to both baseline and follow-up qualitative interviews (see Table 2) which were 'Suicide is difficult to talk about', 'Participation benefited me', 'Participation is worth it', 'Contextual factors influence experience of participation' and 'Impact of participation over time'.

3.3.1. Theme 1: suicide is difficult to talk about

There were two ways in which talking about suicide experiences and thoughts were challenging, albeit, in ways that were manageable:

i) Distressing topic

Discussing experiences of suicide was, at times, difficult, painful and upsetting for participants, but nevertheless considered inevitable.

"I don't think its enjoyable to actually talk about suicide, you know, no one's gonna walk in a room and be like 'Hey it's so exciting'. I don't think anyone's gonna be like that you know?" (C005)

ii) Struggling to articulate

Some participants found it difficult to talk about suicide, either describing it as hard to reflect on or hard to articulate their thoughts, feelings and/or suicidal experiences "I don't know how to, I don't know how to explain it." (C021)

Table 2
Coding framework for qualitative analysis, adapted from Littlewood et, al. (2019).

Theme	Codes	Definition	Source
Suicide is difficult to talk about	Distressing topic	Topic of suicide is viewed as generally distressing	Littlewood et al. (2019)
	Struggling to articulate	Found it hard to put into words how to express suicide experiences and how talking about these is difficult	New inductive code
	Manageable distress	Distress experienced when talking about suicide is manageable. Participant feels able to 'get through'	Littlewood et al. (2019)
Participation benefitted me	Increased self-understanding	Taking part has enabled an increase in a sense of awareness or understanding about participant's experience	Littlewood et al. (2019)
	Therapeutic gains	Talking provided a release. References to participation being like therapy. Taking part has directly helped participant in their own 'recovery'	Littlewood et al. (2019)
	Feeling understood	Seen as valuable to have someone who is seen as an expert in suicide to talk to about suicide – this extends into feeling like someone is really listening and understanding	New inductive code
Participation is worth it	Enjoyable experience	Taking part was enjoyable	Littlewood et al. (2019)
	Trade-off in helping others	Taking part helps other people but can cause distress to the participant themselves – this is seen as 'worth it' for the greater good of helping others	New inductive code
Contextual factors that influence experience of participation	Valuing research	General belief in the good of taking part in suicide research makes it worthwhile	Littlewood et al. (2019)
	Perceptions of wellbeing	Whether the participant is feeling generally well may impact participation. Bad days may equal a hard time participating. Effects and side effects of medication may also make participation harder.	New inductive code
	Assessment Methods	Data collection methods, e.g. face to face questionnaires, affect experience of participation – they can quell or enhance initial nerves or apprehension	New inductive code
	Previous experience of talking about MH and suicide	Participant feels experienced in talking about their mental health and suicide so	Littlewood et al. (2019)

Table 2 (continued)

Theme	Codes	Definition	Source
Impact of participation over time	Short term impact	finds it easy to talk in a research context Any drop or change in mood post-participation, specifically short term lowering of mood and coping mechanisms associated with overcoming this short term dip in mood	New inductive code
	Long term impact	Dip in mood lasts longer than a few hours but overall long term catharsis is the only lasting long-term impact of participation	New inductive code

"I found it quite hard just reflecting back on what I'd been through, I found it very difficult going back, going yeah I have thought about this and yeah I have planned this. I found it very hard." (B005)

iii) Manageable distress

However, although the topic of suicide was viewed as distressing, that distress was seen as manageable. Generally, participants accepted the potential for distress associated with participation.

"I don't find it easy to talk about but I get on with it" (A037)

3.3.2. *Theme 2: participation benefitted me*

Participants reported multiple benefits represented by four sub-themes: i) Increased self-understanding, ii) Therapeutic gains, iii) Value of having an expert ear and feeling heard, and, iv) Enjoyable experience.

i) Increased self-understanding

New insight from participating was characterised by reflecting back on previous times when individuals had felt suicidal compared to now. This comparison was helpful for some to see how far they had come and provided a greater level of self-understanding than they had found elsewhere.

"Urm, it does start me thinking about it but more like in a reflective way like I think about maybe things that I've done and maybe how I was feeling at the time and what if-, what-, what I would do now if it happened again." (A054)

ii) Therapeutic gains

Being part of suicide research provided an opportunity for participants to express what they had been thinking or feeling. The idea of 'release' was important. Talking about suicide provided an opportunity for letting go which individuals had sometimes not felt able to do in other contexts. It was apparent that some participants felt they were carrying negative thoughts and feelings which weighed them down at times.

"It helped me a lot and I enjoyed talking about it because it, like I said it's a weight off my shoulders and I feel a lot lighter now and a bit happier." (C041)

The opportunity to talk was viewed as therapeutic. It provided an opportunity for participants to reflect on what they were going through.

“Erm, it was ... therapeutic you know to, to sort of have a look at myself, how I’m feeling and what I’m going through” (C017)

Participating helped some individuals in their own ‘recovery’ process, providing an opportunity to feel part of a wider community of research participants which could give structure to their days.

“Urm, it’s made me feel more active and like I’m contributing in a small way which has been good for me because I’m not working and I’m not being able to contribute to normal things and normal regular patterns and stuff so it’s been nice. So that’s why I was like yeah give me the paperwork, I’ll do that. Occupy my mind.” (C039)

iii) value of having an expert ear and feeling heard

Some participants valued having someone to talk to, especially a professional including researchers conducting the assessments. ‘Experts’ were perceived as providing a judgement free, safe opportunity to discuss suicidal experiences. Participants felt that an expert was not likely to be shocked by expressions of suicidality because they were probably used to hearing, and working with, such expressions as part of their job roles.

“With professionals I find it really easy to talk most of the time” (C046).

In contrast, some participants felt that it was more difficult to talk about their suicidal thoughts and feelings to people they were close to who had never had suicidal experiences or mental health problems. This included family members who participants believed could be hurt or burdened by them talking about their experiences of suicide which, for some, led them to choose not to talk to their relatives about their experiences.

“the only people that I have strong difficulty talking to about it is people that I am close to that don’t have any mental illness because it’s very difficult for them to understand but when it’s talking to people who do have understanding of mental illness I do find it usually helpful.” (A036)

Without talking to others with shared experience, participants sometimes had felt alone in their thoughts and feelings. Taking part in research about suicide provided an opening to challenge this and participants described how it helped them to realise that they were not the only ones to experience suicidal thoughts and behaviours.

“I’ve been able to like think ‘oh well actually I’m not the only one’, which it makes me sad that other people struggle, but it makes me happy that I’m not the only one” (B028)

iv) Enjoyable experience

There were explicit references to the experience of participating in suicide research being enjoyable. Some participants looked forward to the assessment appointments as an important positive part of their week. Other participants described an overall positive outlook on participation and found it to be an interesting event.

“It’s been something that I’ve been looking up on my diary ready you know to anticipate and stuff so it’s been a good thing in that way, definitely.” (C039)

3.3.3. Theme 3: participation is worth it

Central to this theme was the idea that taking part in suicide research was worthwhile *despite* the potential for distress. Hence, it characterised a trade-off between the anticipated and/or experienced distress and the

benefit to other people, or research in general, of taking part. Two sub-themes were evident: i) Trade off in helping others and ii) Valuing research.

i) Trade-off in helping others

Participants described how they were mindful that others may benefit from any learning that arose from their contribution to the research project. This potential to help others who had experienced similar difficult times made the challenges of taking part feel worthwhile.

“If I can help someone with like suicidal thoughts in any part of my life I’d be well happy, ‘cause I understand what it feels like to wake up in the morning and it’s the first thing in your head and the last thing you think about, so I know what it feels like to have it constantly, dealing with it all the time” (B028)

ii) Valuing research

Participants spoke of their belief in the ‘greater good’ of research. As such, the potential for distress or discomfort during participation was outweighed by the importance of research.

“That’s got to be a positive hasn’t it and anything to do with mental health or if I can help in anyway then that’s a good thing. It’s research, it’s all going to benefit isn’t it so that’s made me feel quite positive in a way.” (C039)

Participants valued feeling part of a wider endeavour and felt that taking part had made them have greater appreciation of the value of research processes.

“It’s been—, because I always think when they say oh this statistic or that statistic I go well how do you know that and well obviously because then they’ve got to ask haven’t they so it’s been nice actually to be a part of that.” (B036)

3.3.4. Theme 4. contextual factors influence experience of participation

This theme encompassed contextual factors which were perceived to impact on the experience of taking part: i. Participants’ wellbeing, ii. Assessment methods, and iii. Previous experiences of talking about mental health and suicide.

i) Perceptions of wellbeing

Participants were concerned about their wellbeing and the influence it may have on their ability to participate in suicide research. Some observed that their mental health fluctuated on a daily basis. This involved accepting that they experienced “*your good days and bad days*” (B005) and that it was important to be aware of their own ability to participate. Furthermore, when participants were not feeling well they were concerned that taking part may exacerbate their mental health problems.

“Urrr probably half and half of [difficult or interesting/useful] depending on who you’re speaking to or ... like ... how far along in the process or like low you’re feeling, anything like that” (A019)

They described how medications they were taking could be helpful meaning they were well enough to participate. However, others expressed how the side effects of medications could cause fatigue and cognitive difficulties that made participating more challenging.

“It’s these tablets, they do slow me down” (D003)

ii) Assessment Methods

Some participants reported that the wording of the suicide questionnaires did not reflect their experiences nor their mental health problems. This was sometimes related to the wording of the actual question itself, and, at other times it was problems with the available response options. Some participants viewed the questions as requiring a correct answer and so found it difficult to respond if their experiences did not meld with the response options.

“I suppose, well, some of my concerns were like the scales and you know the questions because some of the–, a lot of the questions you’re like ‘that’s not really worded in a way that I can make sense’ because you could say this and you could say that and yeah the definitions and the scales aren’t always the best” (C039)

Some participants found the questions themselves to be too invasive or too personal which may have caused apprehension about the assessments and future participation. Some felt anxious about meeting the researcher, concerned about what the questions would be like or worried how the questions might make them feel. These concerns were often allayed once the participant and researcher had met and begun the assessment.

“At first I thought I wouldn’t be able to do it because I felt anxious at first ... but now that it’s done, I’m happy that I’ve talked about it” (C041)

iii) Previous experiences of talking about mental health and suicide

Many individuals described long and complex histories with the

mental health services in which they had frequently been asked to talk about their mental health. Participants reported that because of this type of familiarity they felt unconcerned about taking part in a suicide research project.

“Because I talk to that many people now, I’m just used to it. I mean a while back, I would have but I mean you see that many people that different questions sort of roll out in different ways. You answer them that many times now, it’s s–, you’re just so used to answering them.” (A012)

3.4. Quantitative data

VAS mood scores: Participants’ mood generally improved during an assessment session. VAS scores increased from the beginning to the end of an assessment session for 86% of participants. These improvements were observed during baseline assessments (mean increase from 52.43 (SD = 24.08) to 55.48 (SD = 24.17), Wilcoxon Signed Rank Test Standardised (89) = 3.41, $p = .001$) whereas, there were no significant changes in mood in the follow-up assessments. (The mean drop in mood for 14 participants was just –16.80 [Median = –10].)

Adjective checklist selection: More positive adjectives were chosen than negative (Positive: Mn = 4.43, SD = 2.40, Median = 3.5, range 0–8; Negative: Mn = 3.48, SD = 2.52, Median = 5.0, range 0–8); a difference which was significant (Wilcoxon Signed Rank test standardised [$n = 100$] = 2.56, $p = .01$). One of the most interesting aspects of exploring this adjectival data was identifying participants who had chosen only negative adjectives (but no positive ones) and those who had chosen only positive adjectives (but no negative). A high proportion of the former would have been concerning especially if the suicidal ideation scores of these participants were also high. As illustrated in Table 3, only five

Table 3

The positive and negative adjectives selected by 5 participants who chose only negative adjectives and the 12 participants who chose only positive adjectives, together with the suicidal ideation score (ASIQ). The frequency and percentage of each adjective chosen is also shown for the entire sample (N = 100).

Negative adjectives chosen by participants only selecting negative adjectives (N = 5)										
ID	Uncomfortable	Upsetting	Saddening	Stressful	Tiring	Anxiety provoking	Worrying	Embarrassing	TOT	ASIQ
1	Yes								1	49
2	Yes		Yes	Yes	Yes				4	70
3	Yes	Yes	Yes	Yes		Yes			5	127
4					Yes				1	85
5	Yes	Yes	Yes	Yes		Yes	Yes	Yes	7	82
TOT	4	2	3	3	2	2	1	1	18	
%age	22%	11%	17%	17%	11%	11%	6%	6%		
Positive adjectives chosen by participants only selecting positive adjectives (N = 12)										
	Enjoyable	Interesting	Therapeutic	Worthwhile	Relaxing	Insightful	Calming	Useful		
6	Yes	Yes							2	129
7			Yes	Yes					2	46
8		Yes	Yes	Yes	Yes	Yes		Yes	6	38
9				Yes					1	6
10		Yes	Yes						2	26
11	Yes	Yes	Yes	Yes	Yes		Yes	Yes	7	105
12	Yes	Yes				Yes		Yes	4	22
13	Yes	Yes		Yes		Yes		Yes	5	41
14	Yes	Yes					Yes	Yes	4	126
15	Yes		Yes		Yes		Yes	Yes	5	27
16		Yes	Yes	Yes		Yes		Yes	5	105
17	Yes	Yes	Yes	Yes	Yes		Yes	Yes	7	33
TOT	6	9	7	7	4	4	4	8	49	
%age	12%	18%	14%	14%	8%	8%	8%	16%		
Number and percentage of negative and positive adjectives chosen across all participants (N=100)										
	Uncomfortable	Upsetting	Saddening	Stressful	Tiring	Anxiety provoking	Worrying	Embarrassing	TOT	
TOT	44	46	51	44	35	55	35	38	348	
%age	13%	13%	15%	13%	10%	16%	10%	11%		
	Enjoyable	Interesting	Therapeutic	Worthwhile	Relaxing	Insightful	Calming	Useful		
TOT	43	70	58	74	30	59	34	75	443	
%age	10%	16%	13%	17%	7%	13%	8%	17%		

participants (5% of the sample) chose negative adjectives alone whilst 12 (12%) chose positive alone.

The majority of the sample endorsed a mixture of positive and negative adjectives. The range of suicidal ideation scores for the 5 individuals choosing negative adjectives was 49–127, and for the subgroup choosing only positive adjectives it was 6–129. Hence, there were high and low scores in each sub-group. As can be seen from Fig. 1a and b, the pattern of selection of adjectives was very similar for the total group of participants and the subgroups, with the exceptions of ‘Uncomfortable’ which was selected more by the negative sub-group of 5 compared to the overall sample, and ‘Worthwhile’ and ‘Insightful’ which were selected more by the whole sample compared to the positive sub-group of 12.

3.5. Research question 2: what were the short and long-term effects of participation in assessments during suicide research?

Only qualitative data were used to address this second research question. Central to findings about both the short and long-term impact of taking part were changes in mood, the contrast or similarity of participants’ expectations versus their experience of participation, and positive catharsis.

i) Short term impact

During the qualitative interviews, experiences of a drop or change in mood from the beginning to the end of a baseline or follow-up assessment session were sometimes disclosed. The changes in mood were often

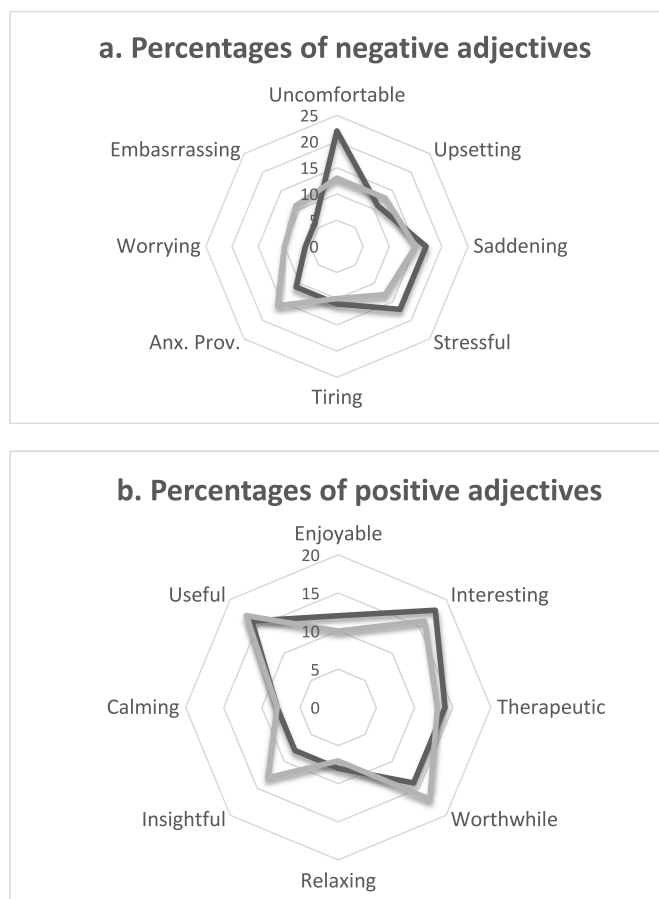


Fig. 1. a and b Radar graphs showing the percentage of negative and positive adjectives chosen by the sub-groups choosing only negative (N = 5) or positive adjectives (N = 12), and for the total sample (N = 100). Subgroups are represented by the grey line.

described as only lasting up to a few hours and often attributed by participants to them talking about suicide.

“After answering questions about suicide, it does make you feel a bit negative” (056B)

Importantly, this mood dip was anticipated and accepted by participants. Furthermore, they developed coping mechanisms to alleviate such mood changes, which included getting back to a normal routine.

“I’m a, tend to listen to the radio. I like listening to world news. And I like um reading books and spending time with family” (056B)

ii) Long term impact

In contrast to the short-term impact of participating, for some, the dip in mood they experienced post-participation lasted for a few days rather than a few hours. Again, participants were able to use their own resources to cope with these sorts of longer lasting mood changes with the caveat that this could be dependent on having a more stable positive outlook from the outset.

“If I’m in a good place I can move forward and forget about it, but if I’m negative point of view, then those questions can be a bit obstructive” (049B)

Long-term catharsis was the central positive effect, which could last far beyond the few days post-participation reported for mood dips. Taking part in suicide research provided an opportunity for release that could be hard to find in other situations. This was particularly important for participants who may have been unable to discuss suicide with their mental health care teams or family. They disclosed that developing a new understanding could then have longer-term benefits.

“Originally, I feel like um later on maybe in a few hours it’ll have a positive impact on my mood, ‘cause I don’t really speak to people about stuff and it’s given me a chance to just talk and um go over some things and it’s like allowed me to like process what I’m thinking” (106C)

3.6. Research question 3: does severity of suicidal thoughts affect the experience of taking part in suicide-related assessments?

As expected, suicidal ideation was negatively associated with VAS mood scores both pre- ($r(100) = -0.21, p = .034$) and post-assessment sessions ($r(100) = -0.30, p = .002$). Lower suicidal ideation scores were associated with better mood at both the beginning and end of assessment sessions. However, there was no significant relationship between suicidal ideation and a change in mood scores ($r(90) = -0.18$), meaning that a decrement in mood across an assessment session was not associated with higher levels of suicidal ideation, and an increase in positive mood across the session was not associated with less severe suicidal ideation. There were also no significant relationships found between suicidal ideation and frequency of positive ($r_s = -0.05$) or negative adjective selections ($r_s = 0.150$). Hence, suicidal thoughts were not associated with positive or negative experiences of participation encapsulated by changes in mood across sessions and the frequency of adjective selections.

4. Discussion

This is the first study to investigate the short and long term impacts of participating in an RCT, an integral part of which involved repeated, and intense, suicide assessments (Gooding et al., 2020). We used a mixed methods, convergent approach comprising qualitative interviews analysed inductively and deductively with a coding framework (Littlewood et al., 2019). We also used a simple measure of mood change from the

beginning to the end of assessment sessions, and an adjective selection task. The main convergent finding was that participation resulted in largely positive experiences in both the short and long term (6–12 months) in that i. mood either became more positive across assessment sessions (baseline time-point) or remained the same (follow-up time point) with changes in mood being unrelated to suicidal ideation severity; ii. more positive than negative adjectives were chosen with suicidal ideation being unrelated to the frequency of positive or negative adjective selection, and iii. participants experienced a sense of catharsis, greater self-awareness, satisfaction with helping others, and being part of a wider community from taking part. These convergent findings are in accord with reports from other studies (Littlewood et al., 2019; Owen 2016; Taylor et al., 2010b).

To observe convergence in this manner using mixed methods over both short and long time periods in people with severe mental health problems, namely, non-affective psychosis, specifically recruited because they were suicidal in the past three months, is striking. This is especially so in the context of documented anxieties about conducting research about suicidal thoughts, urges, plans and acts (Blades et al., 2018; Andriessen et al., 2019a; Lakeman and FitzGerald, 2009). The finding that there was no relationship between the severity of suicidal ideation and changes in mood across sessions nor the frequency of selecting positive or negative adjectives is reassuring, particularly in a suicide focused RCT where suicide assessments can be intense and include probing feelings of hopelessness and being trapped (Gooding et al., 2020). A related finding was that some participants with severe and/or long histories of mental health problems had some degree of habituation to talking about suicidal experiences, which may have transferred to a research setting. It is possible that people who are relatively new to mental health services and whose suicidal experiences are unfamiliar to them do not have this background and would be less comfortable talking about such experiences in an RCT.

Two further findings warrant discussion. First, participants described transient or short-term distress during or immediately after participating in suicide research, which is consistent with previous work (Biddle et al., 2013; Hawton et al., 2003; Littlewood et al., 2019; Taylor et al., 2010b). This short-term distress was accepted as part of the process of participating and the benefit to participants themselves was seen to outweigh that distress. The longer-term impact of participating sometimes reflected a dip in mood lasting a few days rather than a few hours. A novel finding was that participants described having developed their own coping mechanisms to counter both short term and longer lasting slumps in mood, such as, using distractions and taking active measures to be able to move forward. However, an important aspect of implementing these coping mechanisms was that it was facilitative if participants were already in a positive mind-set. When briefing, and indeed debriefing, participants in suicide research studies it may be helpful to alert participants to the potential of mood dips and discuss with them possible coping strategies that they could employ if needed.

The second finding was that some participants found the questions in the assessments to inadequately capture their experiences and, hence, were difficult to respond to. This is important as the assessments used as part of the CARMS RCT (Gooding et al., 2020) are commonplace across suicide research projects (previous examples include: Branley-Bell et al., 2019; Haddock et al., 2019; Pratt et al., 2015; Taylor et al., 2010a). This suggests that it may be important to develop new measures with genuine co-production between Experts-By-Experience and other stakeholders including researchers, mental health charities and mental health professionals.

4.1. Strengths and limitations

The current study has three main strengths. It was the first mixed methods investigation of participants' experiences of taking part in suicide research in the context of an RCT over short and longer-term periods. Previous longitudinal research addressing this issue has only

investigated the experience of taking part in qualitative interviews (Littlewood et al., 2019), used only quantitative approaches (e.g. Reynolds et al., 2006), or included only a brief follow-up time-window of two days (Bender, 2012; Gould et al., 2005). Until now, no research had examined short and longer term effects using convergent and mixed methods of enquiry. As such, this study provides the first multi-faceted insight into the experiences of participation in suicide research. An interesting area for further work would be to compare participants' experiences of questionnaire and qualitative designs.

The second strength was that the participants had all experienced severe mental health problems including recent suicidal thoughts/acts, and non-affective psychosis (Hor and Taylor., 2010). Understanding the effects of participating in suicide research in this vulnerable group is important scientifically, clinically and ethically.

Third, collaborative work with colleagues who are Experts-By-Experience in our PPIE group was central to all the research processes comprising the current study.

There are three limitations which should be highlighted. First, during data collection, the same researcher conducted both the suicide focused assessments and the quantitative and qualitative data generation techniques for the current study. This means that a social desirability bias may have been operating in which the reporting of positive experiences of taking part were favoured (Paulhaus, 1984).

Second, those who agreed to take part in a psychological intervention-based RCT that was focused on suicidal experiences may already feel positive or comfortable talking about suicidal thoughts/acts. It may be that those with less experience of, and interest in, talking about their suicidal thoughts and behaviours, would find additional challenges in taking part in this type of intensive research about suicide.

Third, the sample largely comprised people of White British ethnicity. The finding that trusting experts and valuing research was important may not generalise because mistrust of mental health services has been found to be a barrier to recruiting people of different ethnicities into mental health research more generally (Brown et al., 2014). In-depth research is needed to understand the experiences of diverse and marginalised populations in suicide research.

5. Conclusions

This study has shown that those taking part in a large scale, multi-site RCT of a psychological intervention about suicidal experiences did not report any long lasting negative effects. On the contrary, the main lasting effect was positive, notably encapsulated by a sense of catharsis. Dips in mood as a result of participation were anticipated by participants many of whom enacted their own coping strategies. This is the first study of its kind and offers a valuable insight into conducting suicide research as part of an RCT that is not just acceptable to participants but is embraced by them on a number of dimensions.

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Ethical approval

This study had been reviewed and approved by the National Health Service Health Research Authority (ref: 201644).

CRedit authorship contribution statement

Sarah Peters: Conceptualization, Methodology, Writing – review & editing, Formal analysis, Supervision, Funding acquisition. **Leanne Cook:** Writing – original draft, Project administration, Data curation, Formal analysis. **Donna Littlewood:** Writing – review & editing, Supervision. **Yvonne Awenat:** Writing – review & editing, Funding acquisition. **Richard Drake:** Writing – review & editing, Funding acquisition. **Jodie Gill:** Project administration, Data curation, Formal analysis. **Anna Gorton:** Project administration, Data curation, Formal analysis. **Gillian Haddock:** Writing – review & editing, Supervision, Funding acquisition. **Kamelia Harris:** Project administration, Data curation, Writing – review & editing. **Kerry Hozhabrafkan:** Writing – review & editing. **Charlotte Huggett:** Project administration, Data curation, Writing – review & editing. **Lauren Kirby:** Project administration, Data curation, Formal analysis. **Daniel Pratt:** Writing – review & editing, Funding acquisition. **Patricia Gooding:** Conceptualization, Methodology, Writing – review & editing, Formal analysis, Supervision, Funding acquisition.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Sarah Peters reports financial support was provided by National Institute for Health Research. Yvonne Awenat reports financial support was provided by National Institute for Health Research. Richard Drake reports financial support was provided by National Institute for Health Research. Gillian Haddock reports financial support was provided by National Institute for Health Research. Daniel Pratt reports financial support was provided by National Institute for Health Research. Patricia Gooding reports financial support was provided by National Institute for Health Research. Yvonne Awenat reports a relationship with MIND that includes: board membership.

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