Using my Demons to Make Good: The Short- and Long-Term Impact of Participating in Suicide-Related Research

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Participation in suicide-related research is generally associated with more positive than negative outcomes. However, sparse research has examined the longevity of any effects of participation. Here, we report the first qualitative examination of both the immediate and long-term views of participating in suicide-related research interviews. Thematic analysis indicated that participants had positive experiences, including increased altruism and self-understanding. For some participants, these benefits remained in the months post-participation. Follow-up data revealed that participants can be susceptible to short-term dips in mood, which may not emerge until a few hours/days post-participation. However, any negative effects of participation were confined to the days immediately following the study. Participant-informed recommendations were developed to support researchers in optimizing the well-being of participants in suicide-related research.

Keywords   suicide, suicidal thoughts, qualitative research, participation, ethics

INTRODUCTION

A fundamental principle of conducting ethical research is to maximize possible benefits and minimize potential harm to individuals who choose to participate (World Medical Association, 2013). Specific challenges to this may arise when conducting research with vulnerable people, such as those who experience suicidal thoughts and behaviors. Ethics

committees and researchers have voiced concerns that suicide research may potentially exacerbate participants' suicidal thoughts, feelings, and behaviors (Lakeman & Fitzgerald, 2009b). Research has sought to address this possibility through investigating the impact of participating in suicide-related research. A meta-analysis of 18 studies, which used a range of different methodological designs and involved clinical and non-clinical samples, indicated that being asked about suicidal thoughts and behaviors was not associated with an increase in distress or suicidal thoughts and behaviors (Blades, Stritzke, Page, & Brown, 2018). Although these findings are encouraging, some of these data stem from treatment-based studies which, by their very nature, seek to reduce suicidal thoughts and behaviors or to improve mental health (Aseltine, James, Schilling, & Glanovsky, 2007; Cedereke & Ojehagen, 2002; King, Nurcombe, Bickman, Hides, & Reid, 2003; Vaiva et al., 2006). It is possible that participants' experiences may differ in basic science which seeks to understand suicidal thoughts and behaviors, rather than research evaluating the delivery of an intervention designed to ameliorate such thoughts and behaviors. In addition, the degree to which suicide is discussed during research participation will vary greatly between different methodological designs. For example, it is likely that participants in qualitative interview studies will provide more in-depth information regarding their suicidal experiences than those completing questionnaire-based studies. Consequently, it is important to examine individuals' experiences of participating in different types of suicide-related research.

Investigation of the impact of participation in suicide-related research has used quantitative (Gould et al., 2005; Husky et al., 2014; Law et al., 2015; Reynolds, Lindenboim, Comtois, Murray, & Linehan, 2006), qualitative (Owen, Gooding, Dempsey, & Jones, 2016; Taylor et al., 2010), and mixed-methods approaches (Biddle et al., 2013; Gibson, Boden, Benson, & Brand, 2014; Rivlin, Marzano, Hawton, & Fazel, 2012). Quantitative findings have suggested that participation in suicide research does not significantly increase distress, suicidal thoughts, or suicidal behaviors (Gould et al., 2005; Husky et al., 2014; Law et al., 2015; Reynolds et al., 2006). However, on an individual level, some participants do report a change in mood following participation, either in terms of an improvement or a lowering of mood (Biddle et al., 2013; Gibson et al., 2014). Here, the inclusion of qualitative analyses has generated useful narratives to understand how and why some participants may experience such changes in emotional well-being. For instance, participants in a range of suicide and self-harm–focused research have generally described their experience as positive, which can stem from an increased sense of altruism from contributing to research, and improved mood following the disclosure of suicidal experiences (Biddle et al., 2013; Gibson et al., 2014; Owen et al., 2016; Rivlin et al., 2012; Taylor et al., 2010). In contrast, some participants have found talking about suicidal experiences distressing, and have subsequently become upset or experienced a dip in mood following their participation (Biddle et al., 2013; Gibson et al., 2014; Owen et al., 2016; Rivlin et al., 2012; Taylor et al., 2010). Mixed-methods studies in this area have combined quantitative change scores to monitor alterations in mood from pre- to post-participation, with qualitative data capturing participant's

insights regarding any perceived changes in mood (Biddle et al., 2013; Gibson et al., 2014; Rivlin et al., 2012). These studies revealed that a drop in mood post-participation does not necessarily equate to an overall negative participation experience. Participants reported that they remained pleased to have taken part in the research, irrespective of whether they had found aspects of participation upsetting (Rivlin et al., 2012). Those individuals who experienced some distress believed this to be somewhat inevitable, given the subject matter, and expected the distress to pass quickly (Biddle et al., 2013; Gibson et al., 2014). However, the extent to which such distress is, indeed, transient and/or severe requires empirical investigation.

To our knowledge, only two studies have examined potential delayed impact of participation in suicide-related research (Bender, 2012; Gould et al., 2005). Using an experimental design, both studies found no significant difference between levels of distress reported pre- and two days post-exposure to suicide-related content (Bender, 2012; Gould et al., 2005). Notably, these studies were conducted with high-school and university students. Therefore, further research should examine potential delayed effects of participating in nonexperimental suicide-related studies, and amongst older participants recruited from clinical populations. Ethically, such work is important to ensure that suicide-related research includes necessary procedures to promote the safety and well-being of participants both during and following their involvement.

It would also be prudent to examine the extent to which people experience any longer-term effects from participating in suicide-focused research. A recent systematic review specifically focused on the experience of research participation amongst people bereaved by suicide (Andriessen, Krysinska, Draper, Dudley, & Mitchell, 2018). The review included two studies which showed a difference in the immediate and longer-term impact of participating in psychological autopsy interviews following the suicide of a friend or family member (Hawton, Houston, Malmbergand, & Simkin, 2003; Wong et al., 2010). The proportion of participants who felt "worse than usual: was greatest immediately following participation in the psychological autopsy interview compared with one month later (Hawton et al., 2003; Wong et al., 2010), suggesting the negative effects of participating may not persist. To the contrary, 83% of participants in a follow-up study reported a positive experience of participating in a psychological autopsy study which was conducted 10 years earlier (Saarinen, Hintikka, Vnamäki, Lehtonen, & Lönnqvist, 2000). To our knowledge, no previous research has examined the potential longevity of any negative or positive effects of participation in suicide-focused research, specifically amongst people with personal experience of suicidal thoughts and behaviors. In order for researchers to develop studies which adhere to ethical principles such as minimizing harm to participants, it is important to address this question empirically. Consequently, the current study aimed to investigate perceptions of the short- *and* longer-term impact of taking part in suicide-related research amongst people with lived experience of suicidal thoughts and behaviors. An additional aim of this study was to solicit participant views on how researchers can conduct safe suicide research, with a view to developing participant-informed guidance for researchers which seeks to optimize participant safety and well-being when participating in suicide-focused research interviews.

TABLE 1. **Overview of the Suicide-Related Research From Which Participants Were Recruited**

Study	Aim	Sample	Data collection
Study 1. Littlewood, Gooding, Kyle, Pratt, and Peters (2016)	To understand the role of sleep in relation to suicide pathways in people with experience of depression.	$N = 18$ (10 male, 8 female), aged 20–60, suicidal thoughts and/or behaviors in past year; experienced a major depressive episode(s).	Face-to-face interviews (conducted by DLL), lasting between 50–70 minutes, conducted May–December 2015. Recruitment closed based on data saturation.
Study 2. Harris, Gooding, Haddock, and Peters (2019)	To understand the factors that contribute to psychological resilience to suicidal thoughts and behaviors, in people with experience of non-affective psychosis.	$N = 20$ (10 male, 10 female), aged 23–75, current/past suicidal thoughts and/or behaviors; experienced non-affective psychosis.	Face-to-face interviews (conducted by KH), lasting 15–127 minutes, conducted May–December 2017. Recruitment closed based on data saturation.

METHOD

Participants were recruited from two separate nonintervention studies with clinical populations. Further information regarding this process is provided in the supplementary material (Supplementary Appendix 1). Both had involved taking part in a previous in-depth interview about their experiences of suicidal thoughts and/or behaviors (see Table 1 for an overview of these research studies). The current qualitative, semi-structured interviews were conducted to explore the short-term impact of participation (immediately following participation at time point 1) and the perceived longer-term impact of participation (1–13 months post-participation at time point 2). Thirty-eight people participated in the current interviews at time point 1, 53% were male ($n = 20$), and the sample had a mean age of 42 years (age range: 20–75 years). Twenty-three (61%) participants completed follow-up interviews at time point 2 (Study 1 = 7, Study 2 = 16). All participants were community dwelling, aged 18 years or over, lived in the North of England, and had experience of suicidal thoughts or/and attempts. Fifteen individuals reported that they had experienced suicidal thoughts within the two weeks prior to participating in the suicide-related research. Participant demographic and clinical characteristics are provided in Table 2. Ethical approval was granted by local National Health Service (NHS) research ethics committees (Study 1 reference: 15/NW/0147; Study 2 reference: 17/NW/0211).

TABLE 2. **Participant Demographic and Clinical Characteristics**

Participant ID	Gender	Age	Ethnicity	Relationship status	Mental health diagnosis(es)	Completed follow-up interview (T2)
Study 1 - 1	Male	48	White British	Single	Anxiety, bipolar disorder, borderline personality disorder, depression	13 months
Study 1 - 2	Female	24	White British	Single	Anxiety, depression, PTSD	12 months
Study 1 - 3	Female	33	White British	Single	Anxiety, depression	Did not respond to e-mail invitation
Study 1 - 4	Male	28	White British	Single	Anxiety, depression	Did not respond to e-mail invitation
Study 1 - 5	Male	48	Chinese	Married/ cohabiting	Anxiety	Did not respond to e-mail invitation
Study 1 - 6	Female	51	White British	Single	Depression	Did not respond to e-mail invitation
Study 1 - 7	Male	43	White British	Separated	Anxiety, depression	8 months
Study 1 - 8	Female	32	White British	Single	Borderline personality disorder, depression	9 months
Study 1 - 9	Female	45	White British	Single	Depression	Did not respond to e-mail invitation
Study 1 - 10	Female	20	White British	Married/ cohabiting	Cyclothymia, depression	Did not respond to e-mail invitation
Study 1 - 11	Male	37	White British	Single	Depression	8 months
Study 1 - 12	Female	60	White British	Single	Depression	Did not respond to e-mail invitation

(*Continued*)

TABLE 2. (Continued).

Participant ID	Gender	Age	Ethnicity	Relationship status	Mental health diagnosis(es)	Completed follow-up interview (T2)
Study 1 - 13	Male	20	Mixed	Single	Depression	Did not respond to e-mail invitation
Study 1 - 14	Male	52	White British	Single	Depression	Did not respond to e-mail invitation
Study 1 - 15	Male	35	White British	Married/ cohabiting	Anxiety, depression, obsessive-compulsive disorder	Did not respond to e-mail invitation
Study 1 - 16	Male	28	White British	Separated	Depression, schizoaffective disorder	Did not respond to e-mail invitation
Study 1 - 17	Male	27	White British	Single	Depression, PTSD	5 months
Study 1 - 18	Male	25	White British	Single	No formal diagnosis	Did not respond to e-mail invitation
Study 1 - 19	Female	33	White British	Divorced	Depression, generalized anxiety disorder	5 months
Study 2 - 1	Male	40	White British	Single	Schizophrenia (treatment resistant)	1 month
Study 2 - 5	Female	35	Mixed	Single	Schizoaffective disorder	No. Declined.
Study 2 - 8	Male	40	Mixed	Single	Paranoid Schizophrenia	1 month
Study 2 - 16	Male	73	White British	Single	Depressive disorder, schizophrenia	1 month
Study 2 - 17	Male	43	White British	Single	Paranoid Schizophrenia	1 month
Study 2 - 19	Male	64	White British	Single	Paranoid Schizophrenia	1 month

(*Continued*)

TABLE 2. (Continued).

Participant ID	Gender	Age	Ethnicity	Relationship status	Mental health diagnosis(es)	Completed follow-up interview (T2)
Study 2 - 21	Female	36	Mixed	Single	Unspecified non-organic psychosis	Unreachable
Study 2 - 22	Male	53	White British	Divorced	Paranoid schizophrenia	Unreachable
Study 2 - 23	Male	64	White British	Missing	Paranoid schizophrenia	Unreachable
Study 2 - 24	Male	61	White British	Single	Obsessive-compulsive disorder, schizophrenia	Unreachable
Study 2 - 25	Female	32	White British	In a relationship	Acute psychosis	1 month
Study 2 - 29	Male	29	White British	In a relationship	Depression, psychotic disorder	1 month
Study 2 - 30	Female	56	White British	Single	Schizoaffective disorder	1 month
Study 2 - 33	Female	68	White British	Separated	Chronic schizophrenia	1 month
Study 2 - 40	Female	57	White British	Single	Schizophrenia	1 month
Study 2 - 51	Male	23	White British	Single	Paranoid schizophrenia	1 month
Study 2 - 52	Female	41	White British	Single	Borderline personality disorder, schizophrenia	1 month
Study 2 - 55	Female	51	White British	Single	Paranoid schizophrenia	1 month
Study 2 - 57	Female	33	Black British	Single	Paranoid schizophrenia	1 month
Study 2 - 58	Female	75	White British	Divorced	Schizophrenia	1 month

Data Collection

Time Point 1—Immediate Post-Participation. All participants were given an information sheet and a verbal overview of the study prior to providing informed consent to participate in the research. Face-to-face interviews at time point 1 were conducted by the first and second authors (DLL and KH), directly following participation in suicide-focused research (description of studies in Table 1). These interviews focused on the experience of participating in suicide-related research and followed a topic guide which explored participants': (1) experiences of talking specifically about suicide in the sleep/suicide interview (study 1) or the resilience/suicide interview (study 2), (2) general experiences of participating in the study, and (3) views in relation to how researchers can conduct safe suicide-focused research.

Time Point 2—Follow Up. Subsequently, all participants were invited to complete follow-up interviews conducted by the same interviewer as those at time point 1 (i.e., DLL and KH). Interviews at time point 2 were conducted between one and 13 months post-participation to provide data sampled from a range of longer-term experiences. Participants were given the option to complete these interviews by telephone or face to face. Data collected at time point 1 were utilized to develop a second topic guide for time point 2, which included similar questions regarding experience of participating in the research with additional questions about the extent to which individuals experienced any short-term and/or lasting effects and the nature of such effects from participation. Interviews conducted at both time points were audio-recorded with participants'

consent and transcribed verbatim (by DLL or KH), at which point any identifying information, such as names or places, was removed. Interviews averaged 11 minutes and ranged from 5–20 minutes.

Data Analysis

Impact of Participation. Data were stored and analyzed within NVivo by researchers with expertise in suicide, mental health, and qualitative methodologies (DLL, KH, PG, SP). We chose to analyze the data using a thematic analysis because we sought to identify patterns across the data set that represented participants' experiences (Fereday & Muir-Cochrane, 2006). Thematic analysis was conducted using a hybrid approach as described by Fereday and Muir-Cochrane (2006), whereby data were coded both deductively, with a predetermined coding framework developed from existing literature (Biddle et al., 2013; Gibson et al., 2014; Owen et al., 2016; Taylor et al., 2010), and inductively, to ensure additional salient codes were included within the analysis. The hybrid approach ensured the current analysis was transparent and allowed identification of areas of convergence and divergence from the existing literature. The combination of inductive and deductive coding is the distinguishing feature of Fereday and Muir-Cochrane's (2006) approach to thematic analysis. A deductive codebook was developed through reviewing the qualitative analyses of previous work that has examined participation in suicide-related research (Biddle et al., 2013; Gibson et al., 2014; Owen et al., 2016; Rivlin et al., 2012; Taylor et al., 2010). These studies reported experiences of participation across different topics, populations, and methodologies (see supplementary material, Appendix 2). It
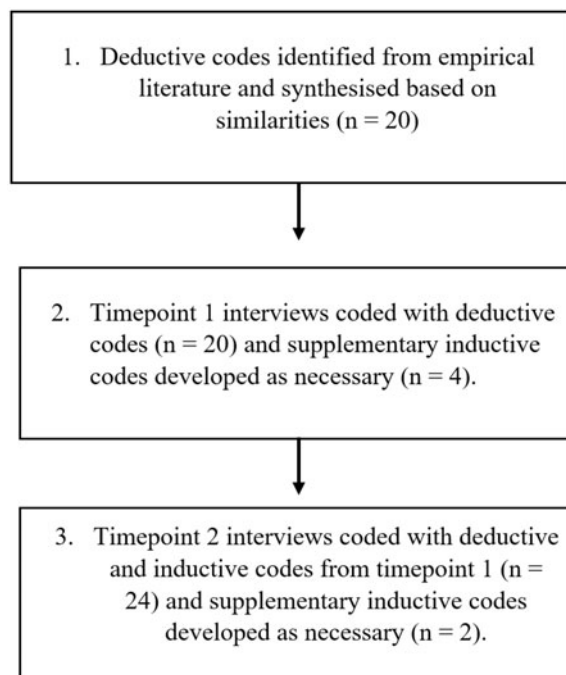
FIGURE 1. *Overview of the hybrid coding process conducted.*

should be noted that the analysis by Rivlin et al. (2012) was not incorporated into the coding framework because this study was conducted in prisons and the site-specific codes could not be generalized to the current research setting.

The coding process had three stages, which are outlined in Figure 1. First, code names and descriptions which addressed the current research question relating to the immediate and long-term views of participating in suicide-related research were extracted from the identified articles (described in supplementary material, Appendix 2). These codes were then reviewed and synthesized based on their similarities and differences, which resulted in 20 codes, as presented in Table 3.

Where codes were taken from a single publication, the original code names were retained. When the same code was identified in multiple sources, the code name and description was developed to encompass key features of the description from each of the original sources (for example see supplementary material, Appendix 3).

Second, data collected from the initial face-to-face interviews were coded by the first and second authors (DLL, KH). Initially, they used the pre-defined set of 20 deductive codes to code the same selection of manuscripts. Any inconsistencies between their application of the deductive coding framework were reviewed, which led to revision of the description for

TABLE 3.   Overview of Inductive and Deductive Coding Framework and Composition in Final Analysis

Final Analysis	Description	Original source	Code name
Participation benefitted me	As a consequence of the interview, participant reports better self-awareness/understanding of own experiences/gained new perspectives.	Biddle et al. (2013); Gibson et al. (2014); Owen et al. (2016); Taylor et al. (2010)	Increased self-awareness/ self-understanding
	Participation was seen as cathartic, participants experienced release and relief as a consequence of sharing experiences.	Biddle et al. (2013); Gibson et al. (2014); Taylor et al. (2010)	Cathartic
	Explicit references to experience of participation being similar to therapy.	Biddle et al. (2013); Gibson et al. (2014); Taylor et al. (2010)	Therapeutic
	Taking part in research motivated participant to seek support related to their mental health. Awareness that research findings may also help to improve understanding of suicidal thoughts which may be translated into improvements in health care provision.	New inductive code (added at time point 1)	Help own recovery
	Opportunity to talk in detail and be heard was seen as positive.	Biddle et al. (2013); Gibson et al. (2014)	Feeling heard
	Good to disclose without censuring, consequence, having to deal with listener passing judgement, or displaying negative reactions or emotions.	Gibson et al. (2014)	Sharing without censure or consequence
	Feels good to know others have had shared similar experiences and that the participant is not just only one.	New inductive code (added at time point 1)	Others have similar experience

(*Continued*)

TABLE 3. (Continued).

Final Analysis	Description	Original source	Code name
My participation will benefit others	Use experiences constructively by participating in research with a view to helping others and improving the understanding of suicidal experiences.	Biddle et al. (2013); Gibson et al. (2014); Owen et al. (2016); Taylor et al. (2010)	Helping others
	A more general perception that research is beneficial.	Taylor et al. (2010)	Believe in research*
Contextual factors influence experience of participation	Current level of well-being influenced experience of participation.	Gibson et al. (2014)	Judging well-being*
	Concern for other participants who were not currently as strong as them, and whether they would have the ability to adequately judge their wellbeing and use that to guide their decision regarding participation.	Gibson et al. (2014)	Concern for others*
	Current unrelated life events causing participant to feel generally distressed.	Owen et al. (2016)	External distress*
	Specific data-collection method influences the length and depth to which participant is asked to engage with the topic of suicide.	Gibson et al. (2014)	Data-collection method influences disclosure*
	Prior to starting the interview, the participant felt apprehensive/ anxious/nervous.	Biddle et al. (2013); Owen et al. (2016); Taylor et al. (2010)	Initially apprehensive/Nervous
	Participant does not find talking about suicide useful as prefers to process suicidal experiences internally, in their own head.	New inductive code (added at time point 1)	Prefer to process issues internally

(Continued)

TABLE 3. **(Continued).**

Final Analysis	Description	Original source	Code name
	The extent to which the participant has previously spoken about suicide influences how comfortable they feel talking about suicidal thoughts and mental health experiences.	New inductive code (added at time point 1)	Experienced in talking about suicide and mental health
Suicide is a difficult topic to talk about	The topic of suicide is viewed as distressing, irrespective of whether the individual is discussing current or past suicidal experiences.	Biddle et al. (2013); Gibson et al. (2014); Owen et al. (2016); Taylor et al. (2010)	Distressing topic
	Distress experienced seen as acceptable and manageable, stemming from topic rather than research setting and participation can still have positive outcomes, i.e., not mutually exclusive.	Biddle et al. (2013); Gibson et al. (2014); Taylor et al. (2010)	Manageable distress
	Distress associated with shame of experiencing suicidal thoughts and acts.	Biddle et al. (2013)	Shame*
	Distress associated with embarrassment related to experiencing suicidal thoughts and acts	Biddle et al. (2013)	Embarrassment*
	Participant reported that they struggled to articulate or verbalize their suicidal experiences in ways that felt adequate.	Gibson et al. (2014)	Struggle to articulate*
Short-term lowering of mood	Any distress experienced during the interview was seen as transient.	Biddle et al. (2013); Gibson et al. (2014); Taylor et al. (2010)	Transient distress
	Perception that questions about suicide could trigger	Gibson et al. (2014)	Triggering suicide*

(*Continued*)

TABLE 3. **(Continued).**

Final Analysis	Description	Original source	Code name
	suicidal thoughts and behaviors.		
	Lowering of mood following participation in interview that lasts up to a few days.	New inductive code (added at time point 2)	Dip in mood
	Belief that generally when you talk about a topic, it will bring that to forefront of mind.	New inductive code (added at time point 2)	Talking brings topic forefront
No instances coded	Generally found it fun, good, enjoyable, regretted it ending.	Biddle et al. (2013); Taylor et al. (2010)	Enjoyable experience

some codes. The two coauthors then progressed to code the remaining manuscripts. They conducted inductive analysis to detect any relevant data not described by any of the predefined codes. This resulted in the creation of four additional codes (see Table 3). Development of inductive codes was discussed and agreed upon by both coauthors prior to incorporation into the coding framework.

Finally, the first and second authors repeated this process to analyze the follow-up interviews using the 24 codes from the initial analysis. Two additional inductive codes were developed for instances where no existing code fitted the pattern of data generated in the follow-up interviews (see Table 3). This resulted in a total of 26 codes (20 predefined deductive and six additional inductive).

Members of the research team (DLL, KH, PG, and SP) grouped the final 26 codes into themes based on their similarities and differences. Themes were then reviewed against extracted data to judge whether they were consistent and reflective of the dataset. An overview of the final coding framework is provided in Table 3.

Inter-rater reliability analysis. Two researchers, who were independent from the research team, conducted inter-rater reliability analyses during the analytical process. The first independent researcher coded a subset transcripts from both the initial and follow-up interviews using the codebook ($n = 7$). Discrepancies between coding led to revision of the descriptions of some codes to make the boundaries between them clearer (for a specific example see supplementary material, Appendix 4). Next, 20 data extracts were given to the second independent researcher who used the finalized codebook to code the selected data. Inter-rater reliability was calculated as a percentage to show the extent to which coding converged (Boyatzis, 1998). This indicated there was 85% agreement in the coding of excerpts between the coders and second independent researcher.

Guidance for Conducting Safe Suicide Research. A descriptive analysis was conducted to summarize participant views on

practices researchers could adopt to optimize the safety and well-being of those who participate in suicide-focused research interviews. The first and second authors (DLL and KH) extracted data from the interviews which were relevant to the second aim. These extracts were discussed with members of the wider research team (DLL, KH, PG, SP), who grouped the suggestions based on their similarities to produce a resource summarizing the recommendations for researchers working in this area (Table 4).

RESULTS

Experiences of Participating in Suicide-Focused Research Interviews

Participants were recruited from two separate nonintervention studies with clinical participants. Four core themes described the experience of participating in suicide-related research interviews, and were developed from data collected at time point 1 (immediately post-participation)

TABLE 4. **Recommendations for Researchers Conducting Suicide-Related Research**

Discuss the following points with potential participants to ensure they have a clear understanding of potential benefits and risks prior to consent

Recommendation	Illustrative quotes
Give an overview of the possible positive and negative effects that the research could have on the participant	*"To maybe expect a dip in mood for a little while but then ultimately it getting it out there can help and it can improve your self-esteem a little bit 'cause you think well I'm doing something that might help other people in the future."* Study 1, ID17, time point 2
Make the withdrawal process clear.	*"The important thing is to say it's voluntary and you can drop out if you want and not give any reasons."* Study 2, ID024, time point 1
Outline the potential impact of the research findings.	*"What the research is going to be used for so that they can see for themselves whether it's going to be a justification of the research and where's it's going to lead to."* Study 1, ID19, time point 2
Clearly explain the research processes in order to alleviate any apprehension which stems from participants not knowing what to expect.	*"Some people don't realize like, that they talk about their experiences a lot anyway and it's kind of no different really. It's just in a bit of a different setting and [I] think if people knew … what it involved more then I think they'd be more open to trying it."* Study 1, ID8 time point 2 *"You said that if you like to take a break when you like, you can get a drink when you like and you can do that as long as you like, […] as long as you're offering people a comfort break, and if somebody is feeling kind of overwhelmed by talking, the fact that you know you could take it up on a second occasion."* Study 2, ID017 time point 2

(*Continued*)

TABLE 4. **(Continued).**

Discuss the following points with potential participants to ensure they have a clear understanding of potential benefits and risks prior to consent

Recommendation	Illustrative quotes
Explicitly establish the research environment as a nonjudgmental, open setting.	*"Being able to talk about it with someone who's understanding and isn't gonna judge you for what you say 'cause some of the things that go round your head seem quite outrageous and you wouldn't really want to talk about that with most people."* Study 1, ID11 time point 2

Include the following provisions to support and safeguard participants

Recommendation	Illustrative quotes
Start the research interview with topics which are emotionally undemanding to allow the participant to become comfortable before building up to asking about suicide.	*"Don't jump straight in about the whole suicide thing. Let it come."* Study 2, ID029, time point 1
Consider including a condition within the consent form to break confidentiality and refer the participant for health-care support should the participant indicate any current risk of suicidal thoughts or behaviors.	*"Again just make sure you've covered all the base, […] saying if there's anything that bothers you, you'll tell the health care, just make sure all the safeguards are there, 'cause every person with a mental health problem is different, and you don't know how they'll react."* Study 1, ID7, time point 2
Remain in contact with participants post-participation to check their wellbeing and facilitate access to support as necessary	*"It did it made me think quite a bit to be honest, about various things and I must admit I did come down a bit … and I had a few bad days."* Study 1, ID7 time-point 2

and time point 2 (follow-up interviews). A fifth theme was developed exclusively from data collected in the follow-up interviews, namely, "Short-term lowering of mood." Two of these five themes represented positive experiences, in which taking part benefitted participants directly (*Participation benefitted me*) or indirectly (*My participation will benefit others*). Negative experiences of participation were also captured by two themes, namely, "Suicide is a difficult topic to talk about" and post-participation at time point 2, which was "Short-term lowering of mood." An additional theme captured the "Contextual factors which influence experience of participation." Quotations provided include identifiers to state: (1) which study participants were recruited from, (2) whether the data stemmed from time point 1 (immediate) or time point 2 (follow-up) interviews, and (3) the length of follow-up period.

Participation Benefitted Me. Participants experienced a range of personally beneficial outcomes related to their participation in the suicide-focused research interviews. Participation was described as cathartic, providing a release, and some participants explicitly likened it to a thera- peutic encounter.

> You see I love talking about things 'cause it helps me, it's like therapy. It's just good to let things out my chest and stuff. (Study 1, ID2, time point 1)

In addition to, or in lieu of, accessing mental health services, talking about suicide in a research setting provided an opportun- ity to reflect on past experiences which resulted in increased self-awareness and understanding. Here, participants explained that this had given them insight into factors that contributed to their suicidal experien- ces, whilst for others, it had provided them with an opportunity to reflect on the differ- ences between their current self and how they were at times of suicidal crises. In fol- low-up interviews, some people described how they had increased self-awareness or strength, which had remained in the months post-participation.

> And thinking about it and knowing how far I've come over these years. I don't realize much I've actually achieved. … I didn't think I did, but talking about it and thinking about it, I've come a long way over the last eight or nine years. (Study 2, ID29, time point 1)

> I: do you think there's been any longer- term effects from taking part in the study?

> P: Yeah, yeah much more aware of that part of me, erm, and much more aware of what is, you know, what is going on in my head. (Study 1, ID19, time point 2, five months post- participation)

Participants valued the research set- ting as providing a freeing, nonjudgmen- tal space where they could speak openly and felt truly listened to. In contrast, some participants spoke of their reluc- tance to talk to family members or friends about experiences of suicide because they feared that these individuals may react emotionally by being angry, upset, or dismissive.

> I've not had to protect you, 'cause I never talk about it with my parents or my sister, because they would just completely freak and I can't really cope with taking on their emotions as well as my own. (Study 1, ID9, time point 1)

> Openly talking about it isn't something I'd normally do … It's a bit strange talking to someone about it, but it's good to know that I'm not getting judged. Do you know what I mean? I talk to some friends about it and they just don't know what to say or how to act. I don't know if they judge me or not, but it is good to get it out in the open. (Study 2, ID29, time point 2, one month post-participation)

Finally, some participants reflected on being part of a research study in which other people were also participating. They described how they found it comforting to know that they were not the only one who had experienced such difficulties.

> I'm sat here now, knowing that you're doing a study and you're gonna see other people and think, well, I've known this anyway but you're never, you're not alone, you know many people feel suicidal in the world. (Study 2, ID17, time point 1)

My Participation Will Benefit Others. The importance of research into suicide was emphasized by participants. A key motivat- ing factor for taking part in suicide-focused

research for them was the notion that sharing their difficult experiences could potentially improve the understanding of suicide and, ultimately, prevent others from experiencing suicidal thoughts and acts. Some people spoke about how this gave them a sense of accomplishment from volunteering their time to the study.

> I'm glad I've done it yeah, put it that way 'cause I'm, again sort of romanticize a bit 'cause I'm using my demons to make good, I hope something good will come of this. (Study 1, ID4, time point 1)

There was a perception that suicide was something which was not always well understood or even approached by professionals. Participants hoped that, through sharing their experiences, this could help professionals to gain better insight into the problem of suicide and improve the support they might offer people with mental health problems who were suicidal. Some individuals in the follow-up interviews spoke of how participation had given them an increased awareness that more is being done to address mental health problems.

> [The research has affected me] in a good way … People looking into the people and err, recognize a bit more an … the government's putting more money into mental health, so that's good. (Study 2, ID51, time point 2, one month post-participation)

> Anything that like, especially a study what like, that gives you more of an insight and help professionals to try to understand it, then it gives you some hope that erm you're not always be working with people who are looking right through you, know what I mean, erm like a textbook. (Study 1, ID1, time point 2, 13 months post-participation)

Suicide Is a Difficult Topic to Talk About. Participants reported a number of reasons why it was, or could be, difficult to talk about suicide. The act of articulating suicidal experiences and effectively explaining them to another person was perceived to be problematic. Some participants described feeling embarrassed or ashamed about their experiences of suicidal thoughts and/or behaviors and were concerned that people would judge them negatively because of these experiences.

> I wanted to do my best to sort of try and explain to you what's going on, but I don't know. Sometimes it's been muddled in my head. (Study 2, ID52, time point 1)

> I guess it's [suicidal thoughts] a weakness on my part, I'm worried that people pick up on that, that it's erm, something to be ashamed of, I think it's more of a shame than guilt, I don't feel particularly guilty about it but I feel more shame what you might think of me or what someone else might think of me. (Study 1, ID15, time point 1)

Talking about suicide in the research setting was also described as a distressing experience. Some found it to be more upsetting than they had anticipated. That said there was a view that it was somewhat inevitable that talking about suicide could cause someone to feel upset because it is a distressing topic.

> Discussing it brings it back and sort of, it's a sad thing. I just feel. I would feel sad for anyone that's gone through that experience. I think it makes me feel sad for me. (Study 1, ID6, time point 1)

It is noteworthy that negative and positive experiences were not mutually exclusive. Participants often reported

positive outcomes directly alongside their narrative about the more negative consequences of participation.

> Difficult but, I don't know, I think it does feel relieving to talk about it. (Study 1, ID10, time point 1)

> Yeah it can be difficult talking about these things but I think it's a useful thing to do, for err both sides. (Study 1, ID11, time point 2, 8 months post-participation)

Short-Term Lowering of Mood. Follow-up interviews provided insight into the short-term and longer-lasting impact of participating in suicide-related research interviews. Whilst no negative long-term effects were reported, views of the short-term impact of the interview were mixed. Of the participants who provided follow-up interviews, a few experienced a delayed lowering of mood following the interview because talking about their suicidal thoughts and difficult times had brought those issues to the forefront of their minds. However, participants explained that these negative effects were confined to the hours or days post-participation.

> On that day, I just felt a little bit down, just with talking about everything. … but also on the same day I was picked up and I was fine. Just for a couple of hours. (Study 2, ID25, time point 2, one month post-participation)

Two participants reported at time point 2 that they had experienced transient suicidal thoughts following participation in the original research interview, though they did not act on these thoughts. Interviewers explored whether these thoughts were related to study participation. Participants explained that talking about suicidal experiences in the interview had reminded them of these difficult times and brought them to the

forefront of their mind. Neither of these participants had reported negative effects of participation at time point 1 and, for both, the thoughts were limited to the short term following participation. Both participants also found participation beneficial and did not regret taking part in the research despite the transient increase in thoughts of suicide.

> I'm glad I took part in it. … I'm quite happy to talk about things and get it out, it's a good thing in many ways it's just my own ability for my mind to turn things in on themselves so that bad times came but it was a good thing to take part in. (Study 1, ID7, time point 2, 8 months post-participation)

During the follow-up interviews, other participants expressed mixed views regarding the possibility that taking part in suicide-related research could act as a trigger for subsequent suicidal thoughts or acts. Those who didn't feel this was likely explained that they associated participation with more positive outcomes, such as it being beneficial and cathartic to talk about suicide. Where a possible risk was acknowledged by participants, they also supported the need for suicide-related research in order to prevent future suicide attempts.

> It's like when you're doing these tests with cancer and somebody gets the placebo and they don't let them know, and they're not going to get better, it's the same with any research, if you're not going to talk about it [suicide] on the bigger picture there's going to be a lot less people getting better, there's going to be a lot more chance of people on a whole getting the [suicidal] thoughts. (Study 1, ID1, time point 2, 13 months post-participation)

Contextual Factors Which Influence Experience of Participation. The final theme differed from the four other

themes because it did not describe an outcome from participation, but rather acknowledged the ways in which previous experience and current well-being influenced how comfortable participants felt discussing their suicidal experiences within a research setting. Participants identified three key factors. First, the amount of previous experience of talking about suicide and mental health problems facilitated the extent to which they found it easy to talk about suicide. For those who had accessed treatment or support helplines, the act of talking about suicide with professionals had become somewhat normalized.

> I've talked about suicide before because obviously like when you make a suicide attempt you have to talk about it afterwards, so I've talked about it then. I've talked about suicide with like say the Samaritans. I've talked to like, 'cause I've been in the system for so long, and like I've discussed issues so many times with so many different people I'm kind of used to it. So it's like, second nature, so it's like nothing that I've not done before really. (Study 1, ID8, time point 1)

Second, participants indicated that their current well-being may influence their experience of participating in suicide research. Participants were less likely to find participation difficult when discussing suicidal experiences that they perceived to be confined to the past.

> Feet very much on the ground and currently very aware that it [suicide attempt] wasn't something I wanted to do. If you'd asked me this time last year err I probably would have been very upset, very tearful, probably hiding under the table while going through with interview. (Study 1, ID5, time point 1)

> Yeah, it was ok, I think, with me, once the feeling's passed, it's easy to talk

about it. Because it's something at the past … I think, if I find it harder to talk when I'm in the, like state, I'm in the mood, I'm in a low mood, so, I find it gets upsetting when I talk about it but when, when it's passed and I don't feel that way, I find it easier to talk about it. (Study 2, ID30, time point 2, one month post-participation)

Finally, some participants explained at the start of the research interview they had felt apprehensive due to their uncertainty about what to expect or because they did not know the researcher. Consequently, at the start of the interview, some participants reported that they were hesitant to speak openly. However, these concerns dissipated during the interview as the participant became more comfortable.

> I certainly don't open up to you perhaps in the beginning, but I found in the end I could open up and say, yeah, well, this happens. (Study 2, ID55, time point 2, one month post-participation)

Guidance for Conducting Safe Suicide Research

Participants described practice that researchers should (1) follow prior to conducting suicide-focused research interviews and (2) make provisions for within the research procedure in order to support and safeguard participants. The descriptive analysis with accompanying quotations is presented in Table 4.

DISCUSSION

Principal Findings

This is the first investigation of the immediate *and* longer-term impact of

participating in suicide-related research interviews. Consistent with previous research on the immediate impact of participation, findings indicate that participation in suicide-related research is generally associated with more positive than negative outcomes (Biddle et al., 2013; Gibson et al., 2014; Owen et al., 2016; Rivlin et al., 2012; Taylor et al., 2010). Additionally, we provide the first follow-up data to suggest that for some people, these positive outcomes are maintained as a longer-term benefit of participation. Negative outcomes, such as a lowering of mood, were reported immediately post-participation and in the following few days but these were confined to the short term. However, it is important to recognize that whilst some participants reported a lowering of mood, this does not necessarily imply that they are at an increased risk of suicidal thoughts or behavior. It was also noteworthy that even in instances where participants reported negative outcomes they simultaneously experienced positive outcomes as a result of participation.

Analysis of data collected immediately post-participation was largely accounted for by the deductive framework of 20 codes extracted from previous studies in this area (see Table 3) (Biddle et al., 2013; Gibson et al., 2014; Owen et al., 2016; Rivlin et al., 2012; Taylor et al., 2010). However, inclusion of the follow-up interviews across the 13 months post-participation provides new insight into the longer-term experiences of individuals who take part in suicide-related research interviews. Most of those who participated in follow-up interviews reported an absence of a long-lasting impact from participation. Moreover, where any long-lasting impact was reported, they were exclusively positive. Positive impacts that were reported in the months post-participation included increased understanding, self-awareness, and a sense of altruism from having contributed to research. No participant interviewed at follow-up reported any long-term negative outcomes from taking part in the research interviews.

Findings from a recent meta-analysis reported that there were no significant differences in participant levels of distress pre- and immediately post-participation in suicide-related research (Blades et al., 2018). Convergent findings were shown in two experimental studies that measured distress at baseline and two days following exposure to suicide-related content (Bender, 2012; Gould et al., 2005). In contrast to this, two participants in the current study reported a temporary lowering of mood and suicidal thoughts in the days post-participation. This suggests that some participants can experience a delayed drop in mood in the short term following participation in suicide-related research. Consequently, safety protocols developed for research should include provisions to monitor participant well-being both during data collection and across the days following participation.

Central to conducting ethical research is minimizing potential harm and maximizing potential benefits to participants (World Medical Association, 2013). When conducting suicide-related research, the possibility of negatively affecting mental health or suicidal thoughts is a key concern for ethics committee members and researchers alike (Lakeman & Fitzgerald, 2009a,b; Owen et al., 2016). As a reflection of this, ethics committee members and researchers have provided best-practice guidance for conducting suicide research (Lakeman & Fitzgerald, 2009a,b; Owen et al., 2016). Commonly advocated practices include the development of a clear protocol to outline how the researcher will

assess and respond to risk and ensuring that this is communicated clearly to potential participants prior to commencing the study (Lakeman & Fitzgerald, 2009a,b; Owen et al., 2016). Although it is not the researchers' role to provide clinical support, at a minimum researchers are advised to give participants information to facilitate access to support services (Lakeman & Fitzgerald, 2009a,b; Owen et al., 2016). An overview of the safety protocol followed in this study is included in the supplementary material (Supplementary Appendix 5).

Previous guidance for practice has been developed by ethics committees and researchers, but not from the experiences of participants. Here, we have utilized the data collected in the current study to expand such guidance to include a series of participant-informed recommendations to support researchers in maximizing benefits and optimizing participant safety and well-being (see Table 4).

One deductive code identified from the extant literature did not feature in the current analysis (i.e., enjoyable experience; Biddle et al., 2013; Taylor et al., 2010). To clarify, in the current study there were some instances where participants reported that participation was enjoyable. However, this was followed up with probing questions from the interviewer which solicited more specific data about how or why they found it enjoyable, e.g., feeling heard and helping others. This meant that such instances were coded under alternative positive codes, rather than the more generic "enjoyable experience" code.

Strengths and Limitations

The current study has three key methodological strengths. First, this was the first study to examine the longer-term views and experiences of people who have participated in suicide-related research. Follow-up interviews were conducted between 1 and 13 months following participation in the suicide-related research interviews. This allowed the longevity of any positive and negative experiences to be explored across a wide range of time periods. Second, inter-rater reliability analyses were performed by independent researchers to establish the reliability of the coding, which demonstrated very high agreement between the independent researcher and authors (DLL and KH). Third, this study sampled participants who had participated in two separate interview studies which sought to understand aspects of people's suicidal experiences. Interviews were conducted with different clinical populations (unipolar depression and schizophrenia-spectrum mental health problems). Themes were represented across both data sets, which suggests that these findings can be applied to conducting suicide-focused research interviews across clinical populations. However, it should be noted that these findings are biased by the self-selecting approach to sampling. Thus, findings should be interpreted as reflective of people who are willing to discuss their experiences of suicide in research interviews and does not include the experiences of those who choose not to take part. Those individuals may be less likely to perceive benefits in this type of encounter. Hence, this study may *overestimate* the positive benefits of taking part in suicide research for the wider population of people who have experienced suicidal thoughts and behaviors.

The findings should be considered in the context of three main limitations. First, findings are limited to people who participated in suicide-related *qualitative* research and the findings may not

generalize to participating in other research designs. For example, participants in the current study identified the opportunity to speak freely at interview as a positive, whilst participants in questionnaire-based studies reported that fixed questionnaire options failed to adequately represent their experiences (Gibson et al., 2014). However, the convergent findings across the developing body of work in this area suggest some similarities in the participant experiences irrespective of the type of suicide research being conducted (Biddle et al., 2013; Gibson et al., 2014; Owen et al., 2016; Rivlin et al., 2012; Taylor et al., 2010).

Second, the same researcher who conducted the suicide-related research (see Table 1) also conducted the participation-focused interview. Consequently, participants may have been susceptible to social desirability bias whereby they may have felt unable to share negative feedback regarding their experience of participation in the study. Furthermore, due to the existing relationship between the interviewer and participant, it is possible that participants may have felt obliged to take part in the current research study. Therefore, future research should consider including a different researcher to conduct the interviews regarding the experience of participation or providing the option for participants to complete paper- or internet-based methods of data collection akin to the study conducted by Gibson and colleagues (Gibson et al., 2014).

Third, interview duration ranged between 5 and 20 minutes, with an average of 11 minutes. In comparison to broader qualitative research, this may seem extremely short. However, since the focus of the research was very specific, and our participants' experience of suicide research ensured they had a high level of information power (Malterud, Siersma, & Guassora, 2016), some interviews were completed within 5 minutes. Participants were asked a range of questions that covered their general experience of participation, whether participation had impacted their mood, to reflect on whether they had received sufficient information prior to participating and whether they had any suggestions for things that could have been done differently/improved. Interviewers probed responses as appropriate. The briefer interviews reflected instances where participants made succinct responses, though these were no less relevant.

CONCLUSION

Engaging in suicide-related research interviews can bring positive outcomes for the individual participant, which may extend into the long term. However, there is evidence that some individuals may experience a short-term lowering of mood following participation in a suicide-related qualitative interview. That said, it is important to note that this dip in mood does not equate to an increased risk of suicidal thoughts and behavior. Participant data were utilized to provide guidance for researchers that is focused on monitoring and optimizing participant well-being. Future research should investigate the temporal nature of both positive and negative outcomes from participation in different types of suicide-related research and address potential issues of researcher bias within the design.

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SUPPLEMENTAL DATA

Supplemental data for this article can be accessed at publisher's weblink.

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DATA AVAILABILITY

The data that support the findings of this study are available from the corresponding author [DLL] upon reasonable request.

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