First do no harm: using 'ethical triage' to minimise causing harm when undertaking educational research among vulnerable participants

Denise Buchanan & Ian Warwick

Published online: 03 Mar 2021.

Submit your article to this journal

Article views: 1802

View related articles

View Crossmark data

Citing articles: 1 View citing articles

Routledge
Taylor & Francis Group

First do no harm: using 'ethical triage' to minimise causing harm when undertaking educational research among vulnerable participants

Denise Buchanan ⓘD and Ian Warwick ⓘD

ABSTRACT

Although educational researchers will acknowledge that they have a moral imperative to avoid harming their participants whilst carrying out research, it does not necessarily mean that they can describe the nature of what this harm might be or how it can be recognised and so avoided. This is particularly important for those working with vulnerable participants, yet there is limited specificity within the educational literature as to what constitutes harm in such a setting. The article addresses this by de-constructing ethical dilemmas that arose during a research study that was carried out among adult students who had mental health problems, in England. The article outlines how these dilemmas were resolved safely due to preparation before the interviews; the 'ethical triage' employed in the interviews; and the reflexivity practised after the interviews. The article proposes that the issue of defining harm and how to recognise and avoid it, needs to be discussed more among educational researchers and those writing ethical guidelines, especially in relation to interviewing vulnerable participants. Not only will this help to better prepare researchers for when ethical dilemmas arise, but will also promote equity and access to participating in research, for those considered to be vulnerable.

Introduction

In 'Do No Harm', neurosurgeon Henry (Marsh 2014) reflected on the trajectory of his surgical career, in light of the accepted adage from Thomas Inman (c.1860) among medical staff of 'First do no harm' (Sokol 2013). Marsh outlined, alongside stories of successful clinical interventions, some of his less successful surgical cases, in which a few of his patients were left physically and mentally incapacitated after undergoing neurosurgery. Candidly he wondered whether out of inexperience or hubris, he had unwittingly caused preventable harm to these patients by opting to operate in situations in which it would have been better not to. As a former nurse prior to becoming a teacher and researcher, this illustration appealed to the lead author (DB) as a metaphor for the responsibility that educational researchers also must 'do no harm' in the course of their work. This is particularly important in an educational context when carrying out research among participants who had been made vulnerable for health reasons, such as mental health problems, as was the case for the research study on which this article is based. It was during data collection for this study that issues arose relating to the participants' well-being which led to DB realising that although educational researchers are not performing anything as immediately life threatening as neurosurgery, they too must be mindful of ensuring that they do not unwittingly cause harm to participants when involving them in research.

Problematic definitions

As the word well-being does not have a universal definition, in this article we have adopted the definition by Dodge et al. (2012, 230), that well-being refers to the 'balance point between an individual's resource pool and the challenges faced'. Correspondingly, as there is no universal definition of what counts as vulnerable (Bracken-Roche et al. 2017; CIOMS 2016; Van den Hoonaard 2018) we have adopted the definition of vulnerable as referring to 'categories of people (*who*) are presumed to be more likely than others to be misled, mistreated, or otherwise taken advantage of as participants in research' (Levine et al. 2004, 44). In this article we discuss how it may be possible to carry out educational research among vulnerable participants, without causing harm to their well-being. However it is important to acknowledge that just as there is no consensus on defining vulnerable, there is also no consensus on whether researchers should view groups who are deemed as being vulnerable by society, as needing such a targeted approach when it comes to carrying out research among them (Dingwall 2012; Van den Hoonaard 2018). Rather, some scholars argue that given the vagueness of the concept of vulnerability and how it can lead ethics committees to impose unnecessary restrictions on allowing certain groups of people to participate in research, a more universalist approach should be adopted (Shaw et al. 2020). Shaw et al. (2020, 289) argued that as 'vulnerability is a universal feature of the human condition . . . ethical, emotional and psychological risk is a normal feature of doing research with human participants', and so excluding people from taking part in research on account of the contentious label of being vulnerable, denies them the chance to personally benefit from participating. Additionally, it denies vulnerable people the possibility of contributing to research knowledge, that may aid scholarship, practice and society as a whole (for further discussion see Juritzen, Grimen, and Heggen 2011; Levine et al. 2004; Santinele Martino and Fudge Schormans 2018).

What is harm and how can it be recognised?

Before beginning this discussion it is first important to consider what harm might mean in a research context as it is another word which does not have a universal definition, particularly as 'what counts as harmful can be subjective and perceptions of harm may vary among stakeholders' (McDonald, Conroy, and Olick 2017, 78). Consequently, we would surmise that although all researchers will acknowledge that they have a moral imperative to avoid harming participants, it does not necessarily mean that they can describe what constitutes harm and how it can be recognised, despite many textbooks emphasising the need to proceed with caution when involving vulnerable groups in research (Cohen, Manion, and Morrison 2011; Robson 2011; Silverman 2010). For us, harm usually refers to injuring a person physically, morally or mentally and is often cited as being important to avoid in relation to carrying out research among children, the elderly or disabled (ESRC 2020; NSPCC 2020). Furthermore, although there is much guidance as to what may be harmful among social care and health researchers (e.g. Dickson-Swift, James, and Liamputtong 2008; Karnieli-Miller, Strier, and Pessach 2009), less guidance appears within educational research, outside the context of students with learning difficulties (Atkinson 1988; Booth and Booth 1996).

The British Educational Research Association ethical guidelines (BERA 2018 nos. 34–35) noted the need to avoid causing harm to vulnerable participants, but the detail is limited. However they do stipulate that a researcher has a greater responsibility to protect participants who are vulnerable and so preparation beforehand is important, which includes the need to appoint gatekeepers (BERA 2018 no. 25), the people who control access to 'a location where it is hoped to carry out (*the*) research' (Oliver 2003, 39). Another guideline is that the researcher should plan to 'manage any distress or discomfort that may arise' (BERA 2018 no. 34) but although helpful, this suggestion fails to identify how this distress or discomfort might manifest itself. Looking at other ethical guidelines (Association of Social Anthropologists 2011; British Sociological Association 2017), we found a similar lack of specificity . This lack of specificity was reported by Dixon and Quirke (2017) in their analysis of ethical guidance in 18 Sociology textbooks. They

noted that although procedural issues relating to ethics were outlined, there was a distinct lack of engagement with the more complex and nuanced ethical issues that social researchers can face. The most explicit advice identified was from the British Psychological Society (BPS) whose guidelines specified some of the risks that might cause harm to a participant such as psychological discomfort or stress. However, although useful, this definition does not specify how harm may be manifest or allude to issues of temporality in relation to the harm which may arise after the event. This advice suggests that:

> Risk can be defined as the potential physical or psychological harm, discomfort or stress to human participants that a research project can generate … These include risk to the participant's personal social status, privacy, personal values and beliefs, personal relationships (13) … (BPS 2014, 13)

Based on the definition of risk by the NSPCC (2020) in this article we will define harm in a research context as 'anything which may cause distress to a participant as a result of taking part in a research project. This may be prompted by hidden or suppressed feelings or memories being uncovered as well as the participant becoming concerned about matters that are raised in the interview or worries afterwards, about what they shared'.

Seeking to minimise causing harm

Nonetheless, although it is difficult to ascertain from the guidelines the exact nature of how we as researchers can identify what harm actually looks like, it is important that researchers adequately prepare in order to minimise its potentially harmful effects, which we elaborate on in this article. However, as will be shown below, even with such prior knowledge, being well prepared cannot mitigate fully against the unforeseen ethical dilemmas that may arise during the interviews themselves, when a researcher has swiftly to reach a decision within the immediacy of the interview as to the best way to respond. Our suggestion is that those conducting research need to engage in, what we are calling 'ethical triage', to respond appropriately when such dilemmas present. 'Triage' is a word which derives from the French verb 'trier' which means 'to sort' or 'to separate' and refers to how one determines which course of action should take priority when faced with competing persons or events that require immediate attention. Although the word is most commonly used within an emergency medical context, it also has been used within an educational context (e.g. Marks 2014).

In a research context, Oliver (2003, 38) advised that any solution to ethical dilemmas that arise during data collection, should come from considering the 'action which is likely to bring about the greatest good'. This stems from the moral reasoning emphasised by Ross (cited in Hudson 1970, 92–98) who talked of people developing a morality based on prima facie duties or moral obligations to other people. These included trying 'to improve the well-being of others, and also the duty of not harming others', as Ross proposed that although one duty might suggest one course of action, a different prima facie duty might point to something else (Oliver 2003, 38). Consequently, a solution to an ethical dilemma will be contextually dependent (Oliver 2003). We propose that in educational research 'ethical triage' should be carried out to ascertain which actions should take priority over others. Actions taken should: prioritise the well-being of the participant, both in terms of preventing immediate and longer term harm; adhere to the stipulations made when the ethics application was approved; be aligned with the aims of the research and serve the purpose of the research itself; and involve choosing the action that can 'bring about the greatest good' (Oliver 2003, 38).

In this article we ask whether considering the scant guidelines outlined above in relation to harm, if and how it may be possible to avoid causing harm when interviewing vulnerable participants within an educational context. Using data from an original study, conducted by DB, we respond to this question by showing the process DB went through as she encountered unpredictable ethical dilemmas in the course of data collection and how she sought to resolve them, using 'ethical triage'. In addition, the article outlines the preparations we made in order to minimise causing harm during

all stages of the research process, in the hope that such explicit information of what went on before, during and after data collection, can help other researchers to minimise causing harm when involving vulnerable participants in research.

The research study

The study on which this article is based, was part of doctoral work carried out by DB which aimed to ascertain how adults with mental health problems perceived their recent classroom learning to have influenced their sense of well-being (Buchanan 2019; Buchanan and Warwick 2020). DB had trained as a nurse and later practised as a Further Education teacher, which included teaching adults with mental health problems. For the study, an interpretative narrative approach was adopted, with each participant taking part in two semi-structured interviews spaced four months apart, as well as class observations. The interviews were audio recorded, transcribed and analysed using thematic analysis (Braun and Clarke 2006) and stored securely as well as all the participants' details being anonymised.

The research took place in an inner-city Further Education college in England and involved an ethnically diverse group of fifteen participants who volunteered to take part, aged between 18 and 60 years old. All participants had received treatment for their mental health problems such as depression, bi-polar disorder and schizophrenia (see Mind 2017). The participants who took part were from a range of vocational and academic courses provided by the college and the college Mental Health Advisers (MHAs) agreed to be gatekeepers for the study. The MHAs worked in both the college and the hospital provision, to help adults with mental health problems move into education or employment when they were well enough to do so.

Ethical approval

Ethical approval was awarded by the Ethics Sub-committee from the East London National Health Service Trust (NHS) and London University and although this study took place in England, the regulations for ethics committees are shared with the rest of the UK (see Department of Health and Social Care 2011). The actual process for obtaining the NHS approval was arduous as it involved two parts.

(1) Before DB could apply to the NHS for ethical approval, she had to first gain permission from the main gatekeeper, the Head Occupational Therapist (OT) from the Mental Health team at the local hospital. This was necessary because DB wanted to include in the research, students from the discrete cookery class that she taught, and which was run in conjunction with this NHS department. Unfortunately, this permission was initially rejected by the Head OT with little explanation and it was only after DB was able to negotiate a face-to-face meeting with this person, which took months to arrange, that she was able to discuss the OT's concerns and resolve the issue. The Head OT then granted permission, provided that certain inclusion and exclusion criteria were incorporated into the design of the research. These are outlined below (see *Ethical issues*).

(2) The next issue that arose was whether the research would need 'full' NHS approval or not. It transpired that it did not, as it did not meet the criteria that the NHS warranted as constituting a clinical research study, given that it was taking place on college premises. This meant that there was a much shorter application process, which led to the Ethics Sub-committee from the East London NHS Foundation Trust granting ethical permission for the study to proceed, which the university backed.

Steps taken to minimise harm

We adopted a three-step approach to minimising harm among participants – actions taken before, during and after the interviews. The principles that undergirded each step were to prioritise the well-

being of the participants specifically in relation to the ethical approval guidelines as well as attempting to lessen the power relationships that are inherent within any researcher-researched relationship. This was particularly important in light of the warning from BERA (2018 no.19) that attention to power relationships is even more essential in cases where the researcher has 'dual roles', such as in DB's case where she was the researcher and the teacher of five of the participants. Due to this DB was mindful of ensuring that she treated her participants with care and respect at all times, and so strove for a more democratic relationship between herself and the participants, which would in turn lessen the power differentials between them. Oakley (1981) argued that participants should not be exploited as merely 'sources of data' (33), which contrasts greatly with the past paternalistic, asymmetrical relationships that existed between researchers and participants, the latter of whom were then referred to as 'subjects'. To achieve this, reflexivity undergirded DB's actions during the interviews and post-interview as well as after the first and second rounds of interviews and whilst writing up the findings. Reflexivity, is the 'process by which the researcher comes to understand how they are positioned in relation to the knowledge they are producing' (Scott and Morrison 2006, 201–202). Reflections post-interview were carried out with DBs doctoral supervisors, whose professional experiences spanned both education and health, which brought different professional perspectives to the reflective process.

Before the interviews

This was a two-step process in preparation for data collection:

(A) Identifying information on how to interview vulnerable participants safely
(B) Devising a safe working interview plan

A. Identifying information on how to interview vulnerable participants safely

This involved seeking advice from various stakeholders who had experience of working with vulnerable adults, as well as appointing gatekeepers who agreed to help during the whole research process (the MHAs). Additionally, information was sought through identifying literature around the area of interviewing vulnerable participants. In terms of the literature, the most informative guidance that aided our planning came from those from within the healthcare field given their increased experiences of carrying out research among vulnerable participants and sensitive research generally. Sensitive research refers to research that 'potentially poses for those involved a substantial threat, the emergence of which renders problematic for the researcher and/or the researched the collection, holding and/or the dissemination of research data' (Lee and Renzetti 1990, 512), such as people talking about having to face cancer or an imminent death or concerning taboos subjects. Many helpful articles were found within this field (Dickson-Swift et al. 2007, 2009) including explicit advice on planning interviews safely (Dempsey et al. 2016). Historically many of these guidelines were informed by the feminist approach to research, as the feminist ethos of supporting 'social justice and social transformation' and specifically placing 'value on the victims of oppression' (Hesse-Biber 2014, 3, 6) had led to increased research into sensitive subjects such as domestic violence or sexuality. This helped to expand understandings of how best to carry out research involving sensitive subjects as well as encouraging researchers to share what actually goes on in the research interview and promote democracy and reciprocity within a research setting (Oakley 1981, 2000; Stanley and Wise 1983).

B. Devising a safe working interview plan

These preparations included deciding on inclusion and exclusion criteria with the MHAs, as outlined below:

Sampling

- To only invite students who were able to give fully informed consent and to exclude those whom the MHAs decided did not have the capacity to give fully informed consent, in accordance with the Mental Capacity Act (2005) in England and Wales.
- To ensure that no student felt coerced in agreeing to take part, especially as DB taught five of the participants.

Ethical issues

- To recruit participants on the understanding that if their mental health declined during the interview period, they would be removed from the study, to protect their fragility.
- To avoid asking participants directly about their clinical care, as the interviews were not being conducted within a clinical setting or by a clinician.
- To ensure participants understand their right to withdraw from any interview.
- To include in the consent form a clause which explains how the MHAs will be informed if participants show signs of distress during their interviews.

Data collection

- To identify what might cause distress by devising a distress protocol (e.g. Dempsey et al. 2016, 486), in preparation for the possibility that a participant became upset during an interview, as had happened in an exploratory study.
- To consider DB's positionality considering that her university education, ethnicity, and socio-economic standard of living differed greatly from those of the participants. Although none of these attributes could be hidden, being aware of these differentials led DB to try to minimise the power relationships within her interviews, not least because she represented an authority figure as a researcher and teacher. BERA (2018 no. 19) warn of unequal power relationships due to such 'dual roles' and so DB was mindful of not only treating her participants with care and respect at all times, but of also being reflexive about how to lessen the differential power relationships between herself and the participants.

Post interviews

- To offer participants the chance to debrief afterwards with the gatekeepers, should they become upset during the interviews.
- To supply telephone numbers for the MHAs in case participants wish to speak to them later about their interviews.

Ethical dilemmas and resolutions

In this section, short extracts from two of the participants, Santosh and Gordon will be presented as they reflect a few of the different ethical dilemmas that DB had faced. Each will be followed by an outline of some of the reflexivity this aroused when DB and her supervisors discussed what happened post-interview, in an effort to ascertain if DB had managed to minimise causing harm to her participants.

During the interviews: Santosh

Santosh (*all names have been anonymised*), a 40-year old Asian woman had a long history of extreme insomnia, clinical depression and had attempted suicide on several occasions. During Santosh's first interview, she was asked if she had disclosed her mental health problems to other students in her class. She replied:

> No, I was hiding my problems from everyone. And then in an English class, the teacher was reading someone's story and they talked about rape and that really upset me (*as her ex-husband had raped her*). Everybody was looking at me because I couldn't stop crying. It was because of my past but I didn't want anyone to look at me differently, as it wasn't my fault. I didn't want them to abuse me or come and rape me or something.

As Santosh spoke she began to cry, and although she was offered the chance to stop the interview due to her distress, she declined to do so and continued to engage with the whole interview despite crying intermittently. By the end of the interview, Santosh was no longer visibly upset, and DB sought to close the interview safely. To do this she reminded Santosh that she could speak with the MHAs afterwards in person on or by telephone, which Santosh declined. DB then escorted Santosh out of the college as this gave her more time to ascertain whether it would be safe emotionally for Santosh to go home alone, which she wanted to do.

After the interviews: reflexivity in relation to Santosh

As DB reflected on the interview with Santosh, the question arose concerning whether DB should have allowed Santosh to continue with the interview when she became distressed, despite the distress protocol being followed. This questioning was in light of the mandate that researchers should 'reconsider' what they are doing when distress is evident (BERA 2018 no. 34), especially as the warmth and empathy shown by DB may have inadvertently heightened Santosh's level of vulnerability, which led her to open up in a way that may not have been emotionally safe for her to do so (Krayer 2003). On this occasion we concluded that DB had dealt appropriately with the situation but it illustrates the importance of having a distress protocol in place in order to minimise causing harm, as even with a distress protocol in place, the concept of harm can still be problematic and subjective. Also, when DB allowed Santosh to continue being interviewed despite being upset, DB was effectively making her own ethical judgement that it would cause Santosh no further harm to do so. Was this because DB would have been disappointed if Santosh had decided to terminate the interview? If so, this admission reflects the conflicted position a researcher can find themselves to be in when such a situation arises. Dickson-Swift et al. (2007, 343) suggested that the researcher can 'feel simultaneously excited and guilty by the data gathered' in such a situation.

The incident with Santosh also raised the question as to whether participants becoming distressed during an interview was an acceptable part of a research interview. Hollway and Jefferson (2000, 86–87), speaking within the context of feminist research and specifically psychosocial interviewing asked:

> . . . is it necessarily harmful to experience being upset or distressed? It can be reassuring and therapeutic to talk about an upsetting event in a safe context.

Considering this in the context of our study, caused us to ask whether this applied to the context of working with a vulnerable population, especially as BERA (2018 no. 34) states that in these cases, the researcher must bear more responsibility for protecting the wellbeing of the participants. This guideline suggests that although all researchers share a moral responsibility to avoid harm to any participants, there is an even greater responsibility within the context of working with vulnerable groups. Hollway and Jefferson (2000, 87) further argued that the 'conflation of harm and distress can be unwarranted as such a conflation 'tends towards an ethical principle that participants should be left unchanged by their experience of the research'. We would agree with the latter premise that it is based on an incorrect assumption as interviewees 'are active co-participants in the relationship' and so the data collected is 'co-constructed' (Riessman 1993, 87, 31). However, in the context of interviewing vulnerable adults, we would contend that conflating harm and distress is *not* mistaken, particularly as a researcher must consider the impact of their research on the lives of such vulnerable people. Having said that, a systematic review of 31 studies that discussed the experiences of interviewing vulnerable participants for research purposes by Alexander, Pillay, and Smith (2018), concluded that the risks of causing undue upset to the participants were outweighed by the benefits

as expressed by participants afterwards. So, this does suggest that despite vulnerable participants becoming distressed during an interview, it may not necessarily be harmful. Thus, we concluded that as a vulnerable participant may well become upset during a research interview, it is essential that there are appropriate safeguards in place to manage this safely.

During the interviews: Gordon

Gordon was a 57-year-old Caribbean man with a long history of clinical depression and suicidal attempts. In Gordon's first interview he spoke candidly of how his depressive periods affected him, and as he did so, he began to cry:

Gordon: My problem is staying in. I will stay in bed for hours and days and days and sometimes I start crying and crying and if you asked me why I would have no idea and I really plummet and I get very depressed and nothing, nothing happens ... on one of those occasions I tried to kill myself I remember. I had a suicide attempt, and it was the college course and everything.

DB: Have you had any suicidal episodes recently?

Gordon: Just casual thoughts of it. If I go anywhere that's like a high building or railway track or something, I think what it would be like to jump. And then it comes to me, it's got to work 'cos I remember the last time I tried to commit suicide it didn't work. At other times I have these negative voices sometimes – 'You shouldn't be here, you're not as good as them'. I would always think lowly of myself.

At this stage DB moved the conversation on to talking about how Gordon coped with being in college when he felt so low, at which point he stopped crying. The interview was closed safely in the same way DB closed Santosh's.

After the interviews: reflectivity in relation to Gordon

Once Gordon's interviews were complete, he was asked for feedback about his experiences and said that although he had found the interview themselves to be upsetting due to the painful memories they elicited, he did not feel that they would cause him longer term harm. Despite this reassurance, when we came to reflect on this episode, we again questioned whether DB had dealt with the situation in the safest way. Specifically, we wondered whether, if when DB asked Gordon, 'Have you had any suicidal episodes recently?' she had been overstepping her role as a researcher in terms of safeguarding. One could have accused her of acting more in the role of a therapist or clinician and possibly causing further harm and of exploiting Gordon's vulnerability given the warning that vulnerable participants 'cannot easily defend themselves against unwelcome or intrusive questioning' (Booth and Booth 1996, 63). We reflected that the 'ethical triage' DB went through was:

(1) To give Gordon the option to discontinue with the interview. He declined, which then led DB to question whether if by allowing Gordon to continue talking about such painful memories, a medical decline in his mental health could be triggered, either immediately or afterwards, and thus cause harm. Conversely, she was aware that if she suddenly ended the interview abruptly, it could leave Gordon in a dangerous place emotionally.

(2) DB wondered whether she had been right in allowing the interview to continue as Gordon spoke of his suicidal thoughts, nonetheless his inclusion of them seemed to be important to his account of being at college. However, DB had then deliberately steered the conversation onto a less emotive topic, after which Gordon appeared to regain his equilibrium and stop crying. This appeared to have been the right thing to do as DB wanted to minimise Gordon's distress and to avoid contravening the ethical approval stipulation that she was not to discuss the participant's clinical care.

(3) Yet as an ex-nurse DB was aware of the importance of always taking seriously such disclosures of self-harm and that it was important for Gordon to know that DB had 'heard' what he had just disclosed. Also, she believed that Gordon must have felt emotionally safe with her to have revealed such personal information in the first place, despite it commonly being a taboo topic of conversation.

(4) Part of allowing Gordon to continue in the interview despite his upset, was in the knowledge that this issue could be followed up by the MHAs, as outlined in the consent form, if Gordon wished it; he didn't.

Although our collective reflexivity led us to conclude that this incident had been handled safely, it highlighted again, not only how ethical dilemmas can occur even with a researcher is well prepared, but also how much power a researcher has in influencing the direction of an interview, through their choice of questions. This serves as a reminder of the potential harm that could be caused given that the decision to proceed even when a participants is visibly upset, has to be made in the immediacy of the moment and by the researcher alone.

Reflexivity in relation to the researcher's role

BERA (2018 no. 84) highlight the need for a researcher to be reflexive in relation to their own well-being as there is a growing acknowledgement that qualitative research is an 'embodied experience', of which there is 'very little empirical evidence'(Dickson-Swift et al. 2009, 61). In light of this, Fitzpatrick and Olson (2015) stressed the importance of reflexivity for the researcher in relation to themselves, as they themselves can be emotionally harmed by having to listen to distressing stories, as well as possibly feeling guilty or responsible for having caused such upset. Being reflexive, DB came to realise that she had not fully anticipated how upsetting the disclosures might be or how many times she had difficult procedural decisions to make in the moment. Despite the careful preparation beforehand, having to ascertain in the middle of an interview which course of action could cause the least harm, involved much 'emotional labour' (Hochschild 1983). Also, hearing some of their distressing stories triggered painful memories of her own personal experiences of mental health problems both during the interview and re-listening to the interviews when analysing the transcripts. However, the opportunity to discuss these feelings afterwards with the team did help to rebalance the emotional labour of these encounters. The team also discussed whether some of these ethical issues could have been fewer if the interviews had been carried out by an impartial interviewer, who may have been at less risk of over-identifying with the participants stories and possibly biasing the findings. However, we concluded that employing an unknown interviewer may have hindered our initial access to these students, given that the willingness of the NHS gatekeepers to support DB's application to the Ethics sub-committee, had been predicated on a prior working relationship with the lead author. Also, given DB's nursing, educational background combined with her own mental health experiences, we reflected that her breadth of experience and insight was essential in facilitating such in-depth interviews both in terms of the amount of material they elicited as well as the careful handling of the ethical dilemmas that arose. Rather, we concluded that the amount of reflexivity practised throughout this study did help to minimise any potential limitations to the lead author carrying out the interviews. However, we surmised that organising an official debrief afterwards for DB with a suitably trained supervisor or therapist would have improved the study design.

Finally, our team reflected also on whether DB had been wise to share about her own mental health issues with the participants, or whether she had been unconsciously attempting to manipulate the participants in order to encourage them to continue being so honest. Possibly one could argue that DB's identification as a 'fellow' sufferer may have caused participants to reveal even more personal recollections than they intended to, which may have made them potentially more vulnerable. Also, we questioned why some participants were given this information and not others. We

concluded that DB had not consciously wanted to manipulate the participants, but rather to reassure them and that her motives on this occasion were ethically acceptable. Also, that her reason for not disclosing to the other participants was based on not wanting to divert the focus from being on the participants' stories, rather her own.

Postscript: inviting participants back

An interesting postscript to the whole study was that DB invited the participants back for a presentation of the findings of the study (four years post- interview) at the college where the study had taken place. Ten of the fifteen participants responded to the invitation and the presentation was arranged in conjunction with the MHAs. Santosh attended and said that she was keeping well mentally and felt positive about her life but Gordon did not reply to the invite nor attend, leaving DB to wonder how his life has progressed since the time of the interviews. The presentation was organised around an afternoon tea party with cakes baked by DB, and although the presentation of the findings lasted 40 minutes, there was much humour alongside the opportunity for participants to ask questions and comment on the conclusions. There was also an opportunity for the participants to look at a hard copy of the PhD thesis and a hard journal copy containing one of DB's articles; they spoke of particularly enjoying seeing these tangible results and also of feeling very proud to have contributed to DB gaining her PhD as well as enjoying the experience of taking part. Finally they spoke of feeling proud that what they had contributed may be of benefit to similar students in the future, echoing the altruism that Alexander, Pillay, and Smith (2018) had identified. It appeared that this presentation provided cyclical closure for the participants and contributed to them feeling a sense of achievement.

For DB, although it was a challenge to present the findings in accessible way to a lay audience, who may have challenged her interpretations (which they did not), it did confirm that among those who attended, there was no evidence of them having been harmed by taking part in the study. Also, organising the presentation provided a tangible opportunity for DB to be reciprocal towards the participants (and the MHAs), and counteracted any possibility that the participants had been treated merely as 'sources of data'(Oakley 1981, 33)

Discussion

Harm and well-being

This article explored how an educational researcher can work among vulnerable participants, without causing harm to the well-being of their participant, despite the lack of specificity within many ethical guidelines as to what is meant by harm and how it can be recognised within a research setting. Furthermore, we demonstrated how harm can be avoided if other safeguards have been put in place beforehand to protect the participants' wellbeing. This is of particular importance for researchers who do not have the professional experience and expertise of working with vulnerable adults as DB had, as her experience invariably contributed to her ability to cope and resolve the multiplicity of ethical dilemmas that evolved. Considering this, we outlined the safeguarding steps which researchers should follow, to help them navigate the complexities of researching among vulnerable communities.

However even with these safe measurements in place for our project we found that ethical dilemmas still arose, especially when participants became upset. This led us to consider the question as to whether a participant who became upset during data collection was harmed emotionally. Although we acknowledged that upsetting reminiscences may not be necessarily harmful and may even be cathartic for some participants, in the case of vulnerable participants we have argued that it could be potentially dangerous for them to become distressed within a research context.

In all the examples given, there were no straightforward answers as to the safest course of action that DB should choose. Yet DB was able to resolve these by employing 'ethical triage', as she weighed up the apparent cost or benefit of any course of action, in order to ensure that no harm was caused within the context of the researcher's prima facie duties (Oliver 2003). Nonetheless, it must be recognised that a researcher's 'ethical triage' may be contingent on their own personality, and perceptions of what they believe may cause harm to the well-being of a participant. Consequently, perceiving and avoiding harm seems worryingly subjective given the non-existence of definitive answers; harm truly is a deeply complex concept.

Earlier we proposed that well-being refers to the 'balance point between an individual's resource pool and the challenges faced' (Dodge et al. 2012), so in light of this, what can we conclude about how the well-being of the vulnerable participants was affected by taking part in this study? Our evaluation is that although several participants were challenged by the upsetting memories that were re-awakened in the interview, they did have the resources to cope with this temporary imbalance. Part of these resources were due to their own personal characteristics, but a larger part was due to DB's ability to handle their distress safely. This safe management resulted mainly from preparation *before* the interviews; the *'ethical triage'* employed *in* the interviews; and the r*eflexivity* practised *after* the interview. It was this combination that enabled the participants to regain their equilibrium within this safe environment, with no longer term damage being reported. Had these not been in place, we would ascertain that harm might have been caused.

Moving forward

Considering this we would suggest that more exploration among educational researchers needs to be encouraged in this area, as if educational researchers wish to find ways to interview vulnerable participants safely, it is vital that they prepare well in understanding what harm might look like in this context. Accordingly, this article proposes two preparation mandates for educational researchers, that they:

(1) Gain understandings of the vulnerabilities of their interviewees beforehand and consider some of the potential ethical dilemmas that may arise during interviewing. This will involve learning from gatekeepers or health researchers, who have more experience of undertaking ethically sensitive work. This preparation will be essential to prioritise the well-being of vulnerable participants.
(2) Practise being perpetually reflexive in relation to how the research may be affecting both their participants and them. Pre-arrange post-interview supervision for the researcher.

Finally, we would propose that the educational ethical guidelines for research need to become more explicit regarding what is meant by harm, how it might be recognised and so prevented. This could be aided by encouraging researchers to share the ethical dilemmas they encounter and how they resolved them, to equip other researchers for when they too face similar issues. Not only could this help to minimise the potential for both the vulnerable participants and the researchers to become emotionally harmed, but it could correspondingly contribute to the body of knowledge that can inform future educational research practises among vulnerable groups. Additionally, this knowledge could contribute to international research being carried out among other vulnerable groups outside of educational contexts, such as those who have been traumatised through war or exploitation (e.g. Refugee Studies Centre 2007).

Returning to the illustration given at the commencement of this article (Marsh 2014), although we as educational researchers are not performing anything as life threatening as neurosurgery, nonetheless we need to treat very seriously our ethical responsibilities in relation to causing harm, particularly with vulnerable participants. We would propose that researchers need to understand what is meant by the contestable concept of harm and how it may undermine the well-being of

vulnerable participants in an educational research context. These understandings may enable the researcher to then know how to recognise it, prevent it and how to lessen it being caused, when unforeseen ethical dilemmas arise. Not only will this help to safeguard both the researchers and the participants from being harmed but will promote equality and access for more people who are deemed as being too vulnerable to participate in research studies; an inclusion which could potentially yield benefits at personal, educational and societal levels.

Acknowledgments

Disclosure statement

Notes on contributors

Denise Buchanan currently works as a Research Associate at UCL Institute of Education, on a longitudinal study looking at the well-being of children who struggle academically in the classroom and teaches on the MA Education. Her main interests are mental health, health inequalities and education following her many years of teaching in a Further Education college.

Ian Warwick's research and teaching has focused on the interface of health and education, particularly in the fields of mental health and emotional wellbeing, sexualities and sexual health, young people's health and wellbeing, healthy and health promoting schools and colleges. He is the Programme Leader for the MA Education, Health Promotion and International Development at UCL Institute of Education.

ORCID

Denise Buchanan 🔵 http://orcid.org/0000-0003-3607-6974
Ian Warwick 🔵 http://orcid.org/0000-0001-5292-756X

References

Alexander, S., R. Pillay, and B. Smith. 2018. "A Systematic Review of the Experiences of Vulnerable People Participating in Research on Sensitive Topics." *International Journal of Nursing Studies* 88: 85–96. doi:10.1016/j.ijnurstu.2018.08.013.
Association of Social Anthropologists. 2011. "Ethical Guidelines for Good Research Practice." https://www.theasa.org/downloads/ASA%20ethics%20guidelines%202011.pdf
Atkinson, D. 1988. "Research Interviews with People with Mental Handicaps." *Mental Handicap Research* 1: 75–90. doi:10.1111/j.1468-3148.1988.tb00006.x.
BERA. 2018. "Ethical Guidelines for Educational Research." https://www.bera.ac.uk/wp-content/uploads/2018/06/BERA-Ethical-Guidelines-for-Educational-Research_4thEdn_2018.pdf?noredirect=1
Booth, T. I. M., and W. Booth. 1996. "Sounds of Silence: Narrative Research with Inarticulate Subjects." *Disability & Society* 11 (1): 55–70. doi:10.1080/09687599650023326.
BPS. 2014. "Code of Human Research Ethics." https://www.bps.org.uk/sites/bps.org.uk/files/Policy/Policy%20-%20Files/BPS%20Code%20of%20Human%20Research%20Ethics.pdf
Bracken-Roche, D., E. Bell, M. E. Macdonald, and E. Racine. 2017. "The Concept of 'Vulnerability' in Research Ethics: An In-depth Analysis of Policies and Guidelines." *Health Research Policy and Systems* 15. doi:10.1186/s12961-016-0164-6.
Braun, V., and V. Clarke. 2006. "Using Thematic Analysis in Psychology." *Qualitative Research in Psychology* 3 (2): 77–101. doi:10.1191/1478088706qp063oa.
British Sociological Association. 2017. "Statement of Ethical Practice." https://www.britsoc.co.uk/media/24310/bsa_statement_of_ethical_practice.pdf
Buchanan, D. 2019. "Five Years Ago I Was on Suicide Watch . . . Now I'm in College Gaining a Qualification." *Journal of Further and Higher Education* 1–13. doi:10.1080/0309877X.2019.1612861.

Buchanan, D., and I. Warwick. 2020. "Supporting Adults with Mental Health Problems through Further Education." *Health Education Journal* 1–12. doi:10.1177/2F0017896920929739.

CIOMS. 2016. *International Ethical Guidelines for Health-related Research Involving Humans*. Geneva, Swizterland: CIOMS.

Cohen, L., L. Manion, and K. Morrison. 2011. *Research Methods in Education*. 7th ed. Oxford, UK: Routledge.

Dempsey, L., M. Dowling, P. Larkin, and K. Murphy. 2016. "Sensitive Interviewing in Qualitative Research." *Research in Nursing & Health* 39: 480–490. doi:10.1002/nur.21743.

Department of Health and Social Care. 2011. *Governance Arrangements for Research Ethics Committees*. Leeds, England. https://www.gov.uk/government/publications/health-research-ethics-committees-governance-arrangements

Dickson-Swift, V., E. James, and P. Liamputtong. 2008. *Undertaking Sensitive Research in the Health and Social Sciences Managing Boundaries, Emotions and Risks*. Cambridge; New York: Cambridge University Press.

Dickson-Swift, V., E. L. James, S. Kippen, and P. Liamputtong. 2007. "Doing Sensitive Research: What Challenges Do Qualitative Researchers Face?" *Qualitative Research* 7 (3): 327–353. doi:10.1177/1468794107078515.

Dickson-Swift, V., E. L. James, S. Kippen, and P. Llamputtong. 2009. "Researching Sensitive Topics: Qualitative Research as Emotion Work." *Qualitative Research* 9 (1): 61–69. doi:10.1177/1468794108098031.

Dingwall, R. 2012. "How Did We Ever Get into This Mess? The Rise of Ethical Regulation in the Social Sciences." *Studies in Qualitative Methodolgy* 12: 3–26. doi:10.1108/S1042-3192(2012)0000012004.

Dixon, S., and L. Quirke. 2017. "What's the Harm? The Coverage of Ethics and Harm Avoidance in Research Methods Textbooks." *Teaching Sociology* 46 (1): 12–24. doi:10.1177/0092055X17711230.

Dodge, R., A. Daly, J. Huyton, and L. D. Sanders. 2012. "The Challenge of Defining Wellbeing." *International Journal of Wellbeing* 2 (3): 222–235. doi:10.5502/ijw.v2i3.4.

ESRC. 2020. "Research with Children and Young People." https://esrc.ukri.org/funding/guidance-for-applicants/research-ethics/frequently-raised-topics/research-with-children-and-young-people/

Fitzpatrick, P., and R. Olson. 2015. "A Rough Road Map to Reflexivity in Qualitative Research into Emotions." *Emotion Review* 7 (1): 49–54. doi:10.1177/1754073914544710.

Hesse-Biber, S. N. 2014. *Feminist Research Practice: A Primer*. 2nd ed. Los Angeles, London: SAGE.

Hochschild, A. R. 1983. *The Managed Heart: Commercialization of Human Feeling*. California: University of California Press.

Hollway, W., and T. Jefferson. 2000. *Doing Qualitative Research Differently: Free Association, Narrative and the Interview Method*. Thousand Oaks, CA: Sage Publications.

Hudson, W. D. 1970. *Modern Moral Philosophy*. London: Macmillan.

Juritzen, T. I., H. Grimen, and K. Heggen. 2011. "Protecting Vulnerable Research Participants: A Foucault-inspired Analysis of Ethics Committees." *Nursing Ethics* 18 (5): 640–650. doi:10.1177/0969733011403807.

Karnieli-Miller, O., R. Strier, and L. Pessach. 2009. "Power Relations in Qualitative Research." *Qualitative Health Research* 19 (2): 279–289. doi:10.1177/1049732308329306.

Krayer, A. 2003. "Fieldwork, Participation and Practice: Ethics and Dilemmas in Qualtiative Research." *Sociology of Health and Illness* 25 (1): 134–136. doi:10.1111/1467-9566.03052.

Lee, R., and C. Renzetti. 1990. "The Problems of Researching Sensitive Topics. As Overview and Introduction." *American Behavioural Scientist* 33: 510–528. https://doi.org/10.1177%2F0002764290033005002

Levine, C., R. Faden, C. Grady, D. Hammerschmidt, L. Eckenwiler, and J. Sugarman. 2004. "The Limitations of 'Vulnerability' as a Protection for Human Research Participants." *The American Journal of Bioethics* 4 (3): 44–49. doi:10.1080/15265160490497083.

Marks, R. 2014. "Educational Triage and Ability-Grouping in Primary Mathematics." *Research in Mathematics Education* 16 (1): 38–53. doi:10.1080/14794802.2013.874095.

Marsh, H. 2014. *Do No Harm: Stories of Life, Death and Brain Surgery*. London: Phoenix.

McDonald, K., N. Conroy, and R. Olick. 2017. "What's the Harm? Harms in Research with Adults with Intellectual Disability." *Amercian Journal on Intellectual and Developmental Disability* 122 (1): 78–92. doi:10.1352/1944-7558-122.1.78.

Mental Capacity Act. 2005. "Mental Capacity Act." http://ethicsguidebook.ac.uk/Mental-Capacity-Act-118

Mind. 2017. "What are Mental Health Problems?" https://www.mind.org.uk/information-support/types-of-mental-health-problems/mental-health-problems-introduction/#.W-QrEvn7SUl

NSPCC. 2020. "Research with Children: Ethics, Safety and Avoiding Harm." https://learning.nspcc.org.uk/research-resources/briefings/research-with-children-ethics-safety-avoiding-harm

Oakley, A. 1981. "Interviewing Women: A Contradiction in Terms." In *Doing Feminist Research*, edited by H. Roberts. Routledge & Kegan Paul.

Oakley, A. 2000. *Experiments in Knowing: Gender and Method in the Social Sciences*. Cambridge: Polity Press.

Oliver, P. 2003. *The Student's Guide to Research Ethics*. Maidenhead, UK: Open University Press.

Refugee Studies Centre. 2007. "Ethical Guidelines for Good Research Practice." *Refugee Survey Quarterly* 26 (3): 162–172. doi:10.1093/rsq/hdi0250.

Riessman, C. K. 1993. *Narrative Analysis*. Newbury Park, Calif.; London: SAGE.

Robson, C. 2011. *Real World Research*. 3rd ed. Chichester, UK: John Wiley & Sons.

Santinele Martino, A., and A. Fudge Schormans. 2018. "When Good Intentions Backfire: University Research Ethics Review and the Intimate Lives of People Labeled with Intellectual Disabilities." *Forum: Qualitative Social Research* 19: 3/9. doi:10.17169/fqs-19.3.3090.

Scott, D., and M. Morrison. 2006. *Key Ideas in Educational Research*. London: Continuum.

Shaw, R., J. Howe, J. Beazer, and T. Carr. 2020. "Ethics and Positionality in Qualitative Research with Vulnerable and Marginal Groups." *Qualtiative Research* 20 (3): 277–293. doi:10.1177/2F1468794119841839.

Silverman, D. 2010. *Doing Qualitative Research: A Practical Handbook*. 3rd ed. Los Angeles; London: Sage.

Sokol, D. K. 2013. "'First Do No Harm' Revisited." *British Medical Journal* 347. doi:10.1136/bmj.f6426.

Stanley, L., and S. Wise. 1983. *Breaking Out Again: Feminist Ontology and Epistomology London*. 2nd ed. London: Routledge.

Van den Hoonaard, W. C. 2018. "The Vulnerability of Vulnerability: Why Social Science Researchers Should Abandon the Doctrine of Vulnerability." In *The SAGE Handbook of Qualitative Research Ethics*, edited by R. Iphofen and M. Tolich, 305–321. London: Sage Publications.