FEATURE ARTICLE

Ethical suicide research: A survey of researchers

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ABSTRACT: *Research is needed to better understand and respond effectively to people who are suicidal. Involving people who are suicidal in research poses some ethical and pragmatic problems. The ethical problems and difficulties in obtaining approval to involve people who are suicidal in research has contributed to the current paucity of research that explores the suicidal experience. To explore some of these problems, a web-based survey of suicide researchers was undertaken. Researchers identified from published reports were contacted by email and invited to participate in a web-based survey. Researchers were asked to describe any problems they encountered, how ethical problems were negotiated or resolved, and any advice received from human research ethics committees. The main problems identified were accessing the population, maintaining confidentiality, the extent of care owed by the researcher to participants, and the facilitation of support to participants. As with clinical practice, ethical research involving people who are suicidal involves a process of sensitive engagement, and careful consideration and remediation of risk.*

KEY WORDS: *ethical review, ethics, research ethics, suicide.*

INTRODUCTION

Suicide is a pressing concern, and prevention is a priority for health and welfare services throughout the world. In many countries, nurses are involved in population-based, suicide-prevention work and in dedicated roles to improve treatment and care to people who might be suicidal. Most psychiatric and mental health nurses will also provide care and treatment to people who are suicidal or are considered to be at high risk of suicide. However, the research base needed to inform their practice is less well established (Goldsmith *et al*. 2002; Hawton & van Heeringen 2006).

Cutcliffe (2003) argues that there is an urgent need for greater attention to the particular life experiences and the meanings that individuals attach to suicidal experiences.

This call for a more qualitative enquiry to inform practice has also been paralleled by concerns about the exclusion of people who are suicidal from clinical trials (Fisher *et al*. 2002; Pearson *et al*. 2001) and the lack of research to inform care of high-risk groups, such as people diagnosed with mental illness and who are homeless (Christensen & Garces 2006).

There are numerous ethical and pragmatic problems involved in including people who might be suicidal in research (Goldsmith *et al*. 2002). For example, the perceived risk of suicide often leads to extraordinary treatment in psychiatric practice and reduced acceptability of the use of placebo or minimum treatment conditions in clinical trials. Legal and sometimes ethical considerations might oblige the researcher to violate the usual boundaries of confidentiality in research, and accessing research participants who are reluctant to receive care or treatment poses a formidable challenge given cultural taboos and the stigma associated with suicide. Addressing these issues to the satisfaction of review boards and ethics committees can pose an obstacle to commencing research and could potentially impact on the validity or credibility of research findings. This paper reports on a survey of

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suicide researchers' perceptions of ethical problems they have encountered and how these were resolved.

BACKGROUND

Mishara and Weisstub (2005) outline three stereotypical ethical positions towards suicide and suicide prevention, which will influence how ethical issues are identified and resolved in research: The moralist position holds that suicide is unacceptable and that protection of life is a prima facie principle or duty. The clinician, researcher, and in some cases, the bystander might be morally obliged to intervene to prevent suicide. The libertarian view (Szasz 1999) holds autonomy as the most fundamental ethical principle and would defend freedom of choice to take one's own life and place no moral obligation on the researcher to intervene to prevent suicide. The relativist position encompasses a consideration of the context or consequences of action or inaction. The obligation to prevent suicide will depend on an analysis of the circumstances. Mishara and Weisstub (2005) bring these perspectives to bear on issues related to suicide research, such as obtaining informed consent and disclosure of information to third parties, and illustrate that from each ethical position, different responses might be justified. They suggest that researchers should disclose their moral stance concerning suicide and the values governing their research proposal. However, researchers are not free to undertake their research in any manner they wish, but must make pragmatic compromises and accommodate different viewpoints to obtain institutional and ethical approval.

Ethics and review committees are governed by national codes and guidelines (Irish Council for Bioethics 2004; Ministry of Health 2006; NHMRC 2007; NHS 2001; NIH 1979; Tri-Council 1998). According to Rosnow and Rosenthal (1997), ethical guidelines allow the judgment of the morality of scientific conduct no matter who the researcher is, as long as research situations are similar. For example, The Australian National Statement on Research Involving Humans (NHMRC 2007; p. 13) asserts that the principle of beneficence is expressed by research that minimizes the risks of harm or discomfort to participants. The statement acknowledges that exploring sensitive topics in depth might involve emotional risks, and there should be clear protocols in place for dealing with distress. Furthermore, the chapter on people with mental illness (4.5.2) states that care should be taken to determine whether mental illness increases a person's susceptibility to some form of distress and ways of minimizing the effect of this susceptibility

should be described. Both these sections prescribe a positive duty for the researcher to provide or facilitate access to some form of support or help that can potentially blur the role between researcher and therapist.

Research reports rarely describe ethical problems that arise during the conduct of the study or how these are resolved. For example, in a published report of a follow-up study of 2404 people exploring influences on suicidal thoughts (Gunnell *et al.* 2004), there was no mention of ethical problems or the nature of support provided to people identified as suicidal. However, a more detailed report (Singleton *et al.* 2002) outlined that researchers were trained and provided respondents with contact phone numbers for the Samaritans, National Drugs Helpline, or Sane if they appeared distressed or asked for help.

Guidance notes have been formulated to assist in addressing ethical problems and encourage the inclusion of people in clinical trials (Oquendo *et al.* 2004; Pearson *et al.* 2001). Problems needing to be addressed include determining the capacity of participants to provide consent, negotiating the risk of lethal outcomes, addressing imminent risk, and upholding the rights of people to refuse treatment (Oquendo *et al.* 2004). While some of these issues might be applicable to research in general, there are no formularized guidelines that explicitly detail the ethical problems or solutions specific to working with people who are suicidal in naturalistic (non-clinical) settings, or which address the highly involved relationships that are often characteristic of qualitative research. This survey aimed to describe the main problems that researchers perceive might be or have been associated with research on suicide and how these might be or have been resolved (regardless of methodology), and was part of a larger project, which included a survey of ethics committee members (see Lakeman & Fitzgerald in-press).

ETHICS

The research was approved and monitored by the Dublin City University Ethics Committee (Dublin, Ireland) and James Cook University Human Research Ethics Committee (Townsville, QLD, Australia), and was considered a low-risk form of research. The anonymity of respondents was safeguarded, and respondents were free from any kind of coercion to participate. Participant contact details were all in the public domain, and no unsolicited repeated contact was made to participants or people who chose not to participate.

METHOD

Design

A web-based survey design was chosen as an inexpensive and efficient method to obtain the opinions and responses of researchers and ethics committee members. Web-based surveys have been found to yield similar response rates and responses to paper-based surveys (Denscombe 2006; Kaplowitz *et al*. 2004). The first author's experience of undertaking previous surveys via email suggested that a rich data set could be obtained from computer-mediated questionnaires (Lakeman 2000; Lakeman & Murray 2000). A web-based platform also had the advantage of making the data directly available (without the need for transcription or data cleaning) for computer assisted content analysis, the method chosen to aggregate and represent the views and opinions of respondents.

Sampling

Suicide researchers were identified via a review of suicide-related research published in English language, peer-review journals from 2005 to 2007. The name and email address of the lead author printed on the publication was extracted and entered into a spreadsheet. It was assumed that contact details published within 3 years of the review would be accurate. Only those studies that demonstrated some kind of active engagement with people who were suicidal were included.

Emails were sent to 98 researchers who were listed as contact people. Of these, 18 bounced back as undeliverable. The email included brief information about the project, the contact details of the monitoring ethics committees, and an invitation to researchers to visit a website and complete the survey. A web portal page reiterated information about the project, provided contact details for the researcher, supervisor, and approving ethics committees, as well as a link to request the final report.

Survey instrument

The survey was brief and collected basic demographic information, such as qualifications, institutional affiliation, experience, and methodology of research undertaken. Open-ended questions related to harms and benefits to participants during the research, any ethical problems that arose, the provision of support offered to participants, and advice provided by ethics committees. The questionnaire was trialled by colleagues currently undertaking suicide research (no adjustments were made on the basis of feedback).

Analysis

The web forms/questionnaires were submitted directly into a relational database. Demographic and closed questions were imported into Excel for the descriptive analysis. Open questions were imported into the software package QSR NVivo 7 (QSR International, Melbourne, Australia) for the content analysis. The aim of the analysis was to generate an accurate, uncomplicated, and parsimonious representation of responses. The data set was reviewed sentence by sentence for new ideas or statements. Ideas or statements were clustered into categories or themes. At each point in which a new category or theme was added, existing coding was reviewed. When all data were categorized, the entire data set was reviewed and the categories were reduced to encompass themes where possible. The end-product of this analysis was a comprehensive list of categories under each question with associated verbatim examples. These were used to inform the narrative account of results (below) and checked to ensure that all the main ideas expressed by the respondents were represented.

RESULTS

Twenty-eight researcher surveys were completed. As outlined in Table 1, most respondents were doctorally prepared, based in the UK or USA, and affiliated with a university. Eight researchers had completed one project that involved people who are suicidal, and the remainder had been involved in more than one project (range: 2–22, mean = 10, SD = 7). Researchers were asked to consider a

TABLE 1: *Characteristics of respondents*

Country where respondents were based	Institutional affiliation of respondents	Academic qualifications of respondents
UK (*n* = 10)	Universities (*n* = 18)	Doctoral degrees (*n* = 21)
USA (*n* = 5)	Health service (*n* = 4)	Masters degree by research (*n* = 6)
Australia (*n* = 3)	Government departments (*n* = 3)	Other higher degree (*n* = 1)
Canada (*n* = 3)	Other (*n* = 3)	
Ireland (*n* = 3)		
Other (*n* = 4)		

project they were involved in to address the remaining questions. The methodologies/designs that researchers employed included randomized controlled trials ($n = 3$), case control and cohort studies ($n = 3$), correlational surveys ($n = 3$), mixed method ($n = 6$), epidemiology ($n = 1$), and qualitative surveys ($n = 4$), ethnography ($n = 1$), grounded theory ($n = 5$), and phenomenology ($n = 2$). The kind of research questions that researchers addressed were diverse and included studies on reasons for living, risk factors for suicide, and an in-depth exploration of people's experiences relating to suicide. Some people outlined a range of projects that they had been involved in, including the effects of witnessing a suicide, intervention and prevention programme evaluations, and coping after a suicide.

The following sections summarize the responses to the open-ended survey questions.

Anticipated problems

Researchers were asked what ethical problems they envisaged at the outset of their projects. Problems were anticipated around accessing the population, gaining consent, distress that participants might experience and how to deal with it, vulnerability of respondents to exacerbation of suicide and management of risk, maintaining the scientific validity of the research, and dealing with ethics committees. These themes were typically interlinked as one respondent noted: 'Anticipated ethical dilemmas span the research process from recruitment to dissemination and centre on issues, such as autonomy and informed consent in an evolving process. . . .' The degree of distress that people experience might impact on their capacity to consent and '. . . one expects that participants may be distressed since the topic is distressing'.

Accessing the population was considered an ethical problem that might involve unnecessarily pathologizing the person's experience, pose problems in terms in terms of causing distress to family members, and maintaining confidentiality (particularly in small populations). It was noted that in some cultures, suicide remains a taboo subject and there are broader questions about who should be approached to be involved in research and how to approach them.

Researchers acknowledged that talking about suicide might be distressing, with one stating: 'The main challenge is to ensure that participants feel safe and secure in the interview, and that the distress they feel is no more than they would feel in their normal lives'. One person noted that there was a fine balance between being a researcher and being a clinician.

Several respondents raised the issue of whether or/not talking about suicide raises the risk of suicide and most were concerned about how to assess whether or not someone was imminently suicidal and what to do in such circumstances, and how the validity or credibility of the research could be preserved. Another respondent was concerned about what to do in a study evaluating an intervention if the service was unable to adequately address risk. Some methodologies had inherent problems; for example, the provision of a placebo in controlled trials. Another noted that treatments are often compared to 'treatment as usual', but usual treatment can often involve extraordinary measures for people who are suicidal. Some participants suggested that the paternalistic and overprotective attitudes of ethics committees towards perceived vulnerable groups posed a problem in designing good research protocols.

Safety measures provided

Various measures were described to ensure the safety of participants. These related to approaching and recruiting participants, information and consent, protocols to manage risk, researcher availability, and the provision of support. Many people described approaching or recruiting participants via third parties or 'gatekeepers', some of whom had a duty of care to participants; for example, mental health services or general practitioners. This was also acknowledged as an obstacle for some, who were unsuccessful at recruiting via a government agency and ultimately obtained clearance to contact people by letter.

Most respondents emphasized the importance of providing full and clear information about the implications of involvement in the study, including circumstances in which confidentiality might be breached. Others made guarantees regarding confidentiality, including resisting court subpoenas. Some stated that carers and care givers were involved in the consent process, and another said that their was a minimum 48-hour 'cooling off' period during which people could consider whether or not they wished to be involved, and consent was revisited repeatedly. Some offered phone contact information to help agencies at the time of recruitment. This was the minimum level of support offered to people. Others spoke about liaising with 'gatekeepers' or helping services to ensure their readiness should they be needed, or having sufficient funds or personnel to provide services. Some also stated that they had an 'on call' psychologist or support team available should such help be required.

Protocols were developed which stated how risks were to be assessed and managed, and included such elements as not leaving a person while they were upset. One person

stated that their study was designed and trialled with 'service user groups' to ensure it was sensitive and meaningful. Lastly, the skill, availability, and sensitivity of the researcher were emphasized. Extra time was provided for 'debriefing', discussing issues that arose during the 'process' of the interview or completing the questionnaire. Some offered opportunities to 'follow up' with the researcher by phone if needed. In such instances, the researcher was a health professional and well aware of what formal assistance might be available.

Problems encountered

Most respondents stated that they encountered no actual or unanticipated problems during the conduct of the research. Confidentiality was cited as a problem for four respondents, particularly as it related to approaching young participants or writing up details about unusual reported suicides. Four respondents also acknowledged that the distress of respondents was problematic with people requiring external support. One person stated that it was difficult distinguishing between research and therapy. Methodological problems were raised by people who had undertaken trials; for example, enhancing 'treatment as usual' conditions reduced the effect size of the intervention. One person reported being subpoenaed on several occasions (which was anticipated and successfully resisted).

Ethical review processes

Most respondents stated that they had no particular difficulties obtaining approval, but pointed out that they had been careful to anticipate possible concerns. The issues raised by ethics committees were typically generic concerns, such as clarifying the language used on information sheets and informed consent processes. One respondent noted that '. . . concerns centred around paperwork and were of little relevance to participants'. A respondent was instructed to include a statement in the information sheet that '. . . advised that people sometimes do things because they are being observed, and participants needed to know that they did not have to die to satisfy a researcher'.

Several respondents stated that they found the ethics committees obstructive or generally resistant to the idea of undertaking research around suicide. Lengthy delays and conflicting advice were reported by those who needed multicentre approval. Suicide research-specific comments related to concerns about liability or blame; for example, not exposing health services to adverse publicity or blame for people's suicidal behaviour. Most respondents also stated that they did not receive advice from review boards. One noted that 'Review boards don't give advice, but set limitations and approve or otherwise'. Several, however, recounted being provided with some specific advice; for example, reducing the number of questions to reduce burden, clarifying protocols for dealing with risk, providing exit interviews for people, and finding out as much as possible about those who chose not to participate.

DISCUSSION

This study had a number of limitations. Utilizing a review of recently-published research as a means of identifying researchers will inevitably exclude some potentially-valuable participants, such as those who have work in press, are currently engaged in research, or who have made important contributions to the field outside of the review period. The 28 responses only reflected a response rate of 35% (allowing for emails that bounced back). This rate could have been improved by using a presurvey surface mail contact (Kaplowitz et al. 2004). A snowballing method of recruitment might have served to include other members of research teams rather than just the published contact person for correspondence. People's responses to open-ended questions were also typically short (mean number of words = 127). The anonymous survey method precludes the possibility of exploring people's responses in any great depth or encouraging elaboration on interesting or ambiguous responses.

Suicide research and mental illness

Most researchers undertook projects with people in psychiatric care. Undertaking research with clinical populations, such as psychiatric inpatients, people with particular diagnoses, or attendees of emergency departments is important. A recent meta-analysis of 40 studies found that one-third of people who committed suicide had contact with mental health services, and approximately 45% had contact with primary care providers within 1 month of the suicide (Luoma et al. 2002). The relationship between mental illness and suicide is complex (Tanney 2000). Half of all people who commit suicide and the vast majority of people who think about suicide have no contact with health-care providers. This poses a problem for researchers in terms of accessing the population, and a dilemma in terms of the kind of assessment and support that ought to be provided by the researcher when encountering people who are suicidal with no history of contact with health services. Researchers and registered health professionals need to consider

on what basis and at what point they might be legally (if not ethically) bound to refer the participant to a third party for assessment or otherwise breach confidentiality. Recruiting people who are acutely suicidal in non-clinical settings might be exceptionally difficult in some jurisdictions.

Providing help and support to research participants

Respondents outlined ways in which they addressed suicide risk. Ethical clinical research requires that '. . . the potential risks to individual subjects are minimized, the potential benefits to individual subjects are enhanced, and the potential benefits to individual subjects and society are proportionate to or outweigh the risks' (Emanuel *et al*. 2000; p. 2705). In clinical research, the risks and benefits to be considered are typically associated with the treatment or treatment conditions. While this continues to apply to clinical research involving people who are suicidal, the risk that respondents most commonly cited was that the research participant would commit suicide. The risk of suicide is not so much intrinsic to the research process as to the individual and population. Almost all respondents expressed concern that research involvement might exacerbate suicide, and all researchers provided examples of different ways that they took care to ensure participants were not unduly distressed. This sensitivity and careful provision of information about available support might be the extent of the researcher's positive duty to participants. Research is different from treatment, requires a different set of skills, and carries different responsibilities. Researchers do not generally have a duty to provide treatment or help resources beyond dealing with harm or problems arising from research participation. In research involving people who are suicidal, this might involve spending more time with people, being more available, and having 'debriefing' available to people, as was recommended by some respondents.

The balance of evidence suggests that participation in research that involves interaction with compassionate investigators is beneficial to people, but it of course might not prevent the person from committing suicide at some time. The researcher must however consider and disclose how they might respond if they believe a participant poses an imminent risk of suicide and on what basis they would make such a decision.

Informed consent

Respondents in this survey were concerned about the issue of informed consent, which is generally understood to include the provision of information, the freedom to make a decision free from coercion, and the competence to make a decision. Respondents emphasized the provision of full information about the consequences of involvement in the research. In the companion survey of ethics committee members, a greater emphasis was placed on questions about people's capacity to consent (Lakeman & Fitzgerald in-press). While some disorders might impinge on people's decision-making capacity, a depressed mood has not been found to greatly impact on capacity, although it might disrupt a person's preferences towards not caring about risks or consequences of involvement (Rudnick 2002). Cohen et al. (2004) confirmed that people who are depressed tend to have reasonably good decision-making capacity, but found that both people who are depressed and people diagnosed with schizophrenia are less likely to volunteer for research than controls. Competency might be better thought of as '. . . a product of the relationship between a person and the consent context' (Toshinori & Hidetoshi 2004; p. 495). Thus informed consent should not be a procedure or a product to be obtained, but a process to be negotiated and revisited.

Negotiating ethical research

In some respects, intervention research, such as randomized controlled trials with their emphasis on tight control, will lend themselves more easily to procedural guidelines (Oquendo et al. 2004) than less-controlled forms of exploratory research or qualitative enquiry. Qualitative research and research in naturalistic settings creates difficulties in terms of specifying procedures a priori. A pragmatic solution that was described by some respondents is to ensure that there is a 'safety net' of services to respond to contingencies as they arise.

Cutcliffe and Ramcharan (2002) argue that the methodology of much qualitative research emerges in the context of prolonged researcher–participant relationships and intimate knowledge derived from in-depth interviews. Potential harm and indeed benefits will arise in the context of this relationship, which cannot reasonably be foreseen in advance, and risk-benefit ratios cannot be determined from the outset. They argue for an 'ethics as process' view, whereby the ethics of a study is relational, dynamic, monitored, and revisited frequently over the course of a study. Their recommendations are consistent with many of the respondents in this survey; for example, to establish and build trust, revisit consent and people's rights frequently, sensitively handle ending the relationship, monitor for distress or harm, and to mobilize a 'safety net' of support if necessary.

CONCLUSIONS

This survey adds to the knowledge of ethical and pragmatic issues that arise within research involving people who are suicidal. It represents opinion (albeit informed) rather than consensus on the issues that are important for researchers. Further research might consider building consensus around the most important principles to consider in suicide research. Further research is also needed to inform health professionals, families, and individuals themselves to assist in making sense of and responding to suicide. Nurses are well placed to engage with people who are suicidal, and the accounts of respondents to this survey might assist in negotiating ethical approval and undertaking safe and ethical research.

There are differences of opinion on central issues, such as the extent that researchers ought to intervene to prevent suicide amongst the research community. These reflect different moral positions regarding people's right to suicide, different beliefs about the meaning of suicidal behaviour, pragmatic concerns about liability, and different views on what counts as good research. The resolution of these issues in the context of developing, approving, monitoring, and undertaking research is a practical, and to some extent, a social endeavour that requires accommodation of different positions and compromise.

Ethically-sound research involving people who are suicidal requires scrupulous procedures relating to informed consent, assessment of risk, and access to competent support and assistance for the researcher and participants. As a human endeavour, it requires the researcher to consult, liaise, and negotiate with people who are suicidal and key people in their lives. Researchers must respect participants by demonstrating sensitivity to their vulnerability. Ethical research with people who might be suicidal is not greatly different to good research generally. In some respects, it is also similar to good clinical practice, which requires the development of respectful and trusting relationships contained within organizational boundaries that are renegotiated as the person's circumstances change. One requires some rules or extant guidelines, but most importantly, integrity on the part of the researcher.

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