FEATURE ARTICLE

Identifying Gaps in Suicide Research: A Scoping Review of Ethical Challenges and Proposed Recommendations

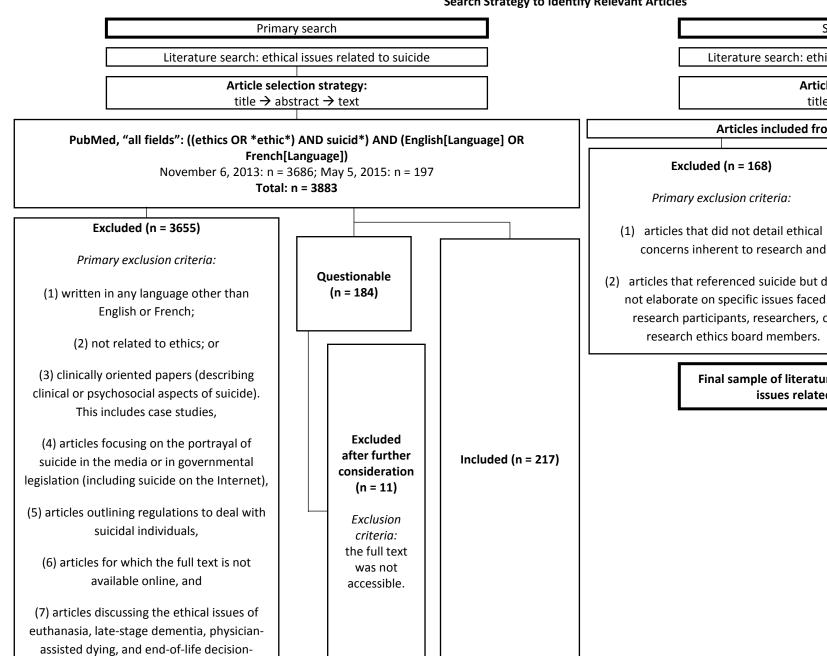
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Figure and tables begin on next page.

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Figure 1.

Search Strategy to Identify Relevant Articles



making.

Secondary search Literature search: ethical issues inherent to suicide research **Article selection strategy:** title → abstract → text

Articles included from original PubMed search (n = 217)

- (2) articles that referenced suicide but did not elaborate on specific issues faced by research participants, researchers, or

Questionable Included (n = 46)(n = 49)

Excluded after further consideration after being reviewed for relevancy (n = 3)

Exclusion criteria: the primary focus was not on suicide research.

Final sample of literature included in scoping review of ethical issues related to suicide research (n = 46)

Table 1.

Representation of Charting Strategy ("Issues mentioned") and Other Information about the Included Articles ("Type" and "Groups focused on")

	Typ	e of	artic	le		Gro	oups	focus	sed o	n in a	articl	es																Issu	ies di	iscus	sed											
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Reference	Review (formal or narrative)	Randomized controlled trial (RCT)	Survey- or questionnaire-based	Interview-based	Conceptual or theoretical	Psychologists	Prisoners	Research ethics board (REB) members	Parents	Currently or previously suicidal	Depression, mania, bipolar, schizophrenia	Nonbereaved individuals/controls	Other	Researchers	Bereaved Individuals	Youth or adolescents	Identification of those needing help	Due to exclusion	Best practice	Research	Deception	Compensation	Resources	Outcome measure	Confidentiality	RCT challenges	General	Stigma	Therapeutic misconception or coercion	Recruitment	Consent	Harmfulness	Population	Researchers' beliefs	Risk or Benefit	REB or institutional review board (IRB)	Burden on researchers	Designing study	Duty to intervene	Feasibility in specific cultural groups	Recommendations and future directions	Long-term benefits or harms
1					X																								Ì		X						X	X			X	
2					X															X				X	X	X	X	X		X		X				X						X
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7			X					X															X		X	X	X			X	X	X	X		X	X	X	X	X			X
∞					X												X	X	X	X	X		X		X	X	X		X	X	X	X		X	X				X		X	
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15					X																X											X				П		
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34	<u>.</u>				41														23		21		41													Щ		
35	X														X							X																

Total	46	45	44	43	42	41	40	39	38	37	36
6						X	X			X	
4								X			
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21	X		X						X		X
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An X represents an ethical issue that was discussed or acknowledged in each paper, even if the issue was mentioned only in passing and was not the main focus of the paper. A rich-coding strategy was adopted, which means that the total counts in each category could equal more than 46 articles and articles could have more than one designation. 1. Boden ZV, Gibson S, Owen GJ, et al. Feelings and intersubjectivity in qualitative suicide research. Oualitative Health Research 2016;26(8):1078-1090. 2. Stanley B. Ethical considerations in biological research on suicide. Annals of the New York Academy of Sciences 1986;487:42-46. 3. Degenholtz HB, Parker LS, Reynolds CF. Trial design and informed consent for a clinic-based study with a treatment as usual control arm. Ethics & Behavior 2002;12(1):43-62. 4. Gibson S, Benson O, Brand SL. Talking about suicide: Confidentiality and anonymity in qualitative research. Nursing Ethics 2013;20(1):18-29. 5. Kim SYH. Benefits and burdens of placebos in psychiatric research. Psychopharmacology 2003:171(1):13-18. 6. Lakeman R, Fitzgerald M, Ethical suicide research: A survey of researchers, International Journal of Mental Health Nursing 2009;18(1):10-17. 7. Lakeman R, FitzGerald M. The ethics of suicide research: The views of ethics committee members. Crisis 2009;30(1):13-19. 8. Mishara BL, Weisstub DN. Ethical and legal issues in suicide research. International Journal of Law and Psychiatry 2005;28(1):23-41. 9, Mugisha J, Knizek BL, Kinyanda E, et al. Doing qualitative research on suicide in a developing country: Practical and ethical challenges. Crisis 2011;32(1):15-23. 10. Prinstein MJ. Introduction to the special section on suicide and nonsuicidal selfinjury: A review of unique challenges and important directions for self-injury science. Journal of Consulting and Clinical Psychology 2008;76(1):1-8. 11. Range LM, Leach MM. Gender, culture, and suicidal behavior: A feminist critique of theories and research, Suicide and Life Threatening Behavior 1998;28(1):24-36, 12. Spirito A. Stanton C. Donaldson D, et al. Treatment-as-usual for adolescent suicide attempters: Implications for the choice of comparison groups in psychotherapy research. Journal of Clinical Child and Adolescent Psychology 2002;31(1):41-47. 13. Stiffman AR, Brown E, Striley CW, et al. Cultural and ethical issues concerning research on American Indian youth. Ethics & Behavior 2005;15(1):1-14. 14. Wilson CM, Christensen BK. Ethical issues relevant to the assessment of suicide risk in nonclinical research settings. Crisis 2012;33(1):54-59. 15. Dazzi T, Gribble R, Wessely S, et al. Letter to the editor: Suicidal ideation and research ethics committees: A reply. Psychological Medicine 2015;45(01):217-218. 16. Hubbeling D. Letter to the editor: Suicidal ideation and research ethics committees. Psychological Medicine 2015;45(01):217-217. 17. Rivlin A, Marzano L, Hawton K, et al. Impact on prisoners of participating in research interviews related to near-lethal suicide attempts. Journal of Affective Disorders 2012;136(1-2):54-62. 18. Cwik MF, Walkup JT. Can

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Table 2. Issues with Methods Used

Торіс	Findings	Unaddressed issues
Psychological autopsy studies	 IRB/REB members' concerns about causing harm to participants made it difficult to conduct research. Empirical studies reported that the majority of interviewed participants did not experience negative effects from their involvement, while a minority did report negative views. Participants found their involvement therapeutic and hoped it would help others in the future. Obtaining consent, recruitment, study design, and determining which support services to offer to upset individuals were challenging. In a few instances, participants became visibly upset and were asked if they wanted to continue. Most authors concluded that psychological autopsies were appropriate and safe. 	 What does harm entail? Are certain aspects of participation perceived as more harmful than others? The articles did not discuss coping strategies, services offered to bereaved individuals, or identifying risk factors that could partially account for respondents' differing views. Participants sometimes mentioned problems during the interview (e.g., lack of support services) that were not further investigated or discussed within the articles.
Randomized controlled trials (RCTs)	 RCTs were mostly conducted to examine the effectiveness of psychopharmaceuticals. Focused primarily on study design, authors were divided about whether RCTs were appropriate for suicide research but remained optimistic that well-designed studies could be acceptable. What constituted an appropriate control group (e.g., a placebo, treatment-as-usual, or psychotherapy group) was heavily debated. Variability is introduced in study designs due to the lack of a standard of care for suicide in clinical settings, researchers' opinion of the acceptability of suicide, services available in community settings. Ensuring external validity of trials is difficult (due to their short duration, low number of participants). Some authors expressed concern that suicidal individuals could be exposed to harm due to strict protocol adherence. 	 Are there other RCT designs that suicide trials could be modeled on that would be more effective? What strategies have researchers in other domains used to combat similar problems (e.g., low recruitment)? What is the most acceptable form of outcome measure that could be used in these sorts of trials?

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Table 3. Involvement of Participants in Research and Associated Ethical Issues

Торіс	Findings	Unaddressed issues
Vulnerability of research participants	 Suicidal individuals are often excluded from the very research that is designed to help them. Research is seen as being both directly and indirectly harmful. Empirical findings suggest that asking participants about their suicidal thoughts did not increase the frequency of their occurrence. Qualitative or participatory research strategies would be useful to engage suicidal individuals and obtain data about what they find acceptable. 	 Should research restrictions be relaxed if the link between suicidal ideation and suicide attempts is not clear? How can the direct and indirect harms be mitigated through study design? How can we facilitate the inclusion of suicidal individuals or those who are considered to have the same or similar vulnerabilities in research trials?
Individuals who do not want to participate in research	 There are great uncertainties about (1) whether to permit suicidal individuals who want to withdraw from research to do so and (2) what researchers should do if someone who is suicidal refuses to join their research trial. It is often difficult to determine individuals actual risk of death and their competence to consent to or withdraw from research. This poses problems for resource allocation, among other things. There is a risk of classifying suicidal individuals as nonsuicidal and vice versa. 	 There is a lack of focus on nontherapeutic research. What options are provided to those who do not want to participate in research? What happens when individuals are not considered competent to withdraw from research and, presumably, are therefore not competent to give their consent to continue being involved? Does the discomfort with allowing potentially suicidal participants to withdraw from therapeutic research indicate that researchers have muddled the distinction between therapy and research? If researchers believe that suicidal participants should remain in their trials for their own benefit, has clinical equipoise been breached? There is very little discussion of what should be done if suicidal individuals are inadvertently recruited to research that is not about suicide.
Involving youth participants	 It is inappropriate to extrapolate findings from adult studies to youths. Recruiting youths is almost impossible due to concerns about vulnerability. Many researchers in this area are also physicians, which could introduce a conflict of interest. The lack of a clinical standard of care means that there are inconsistencies in the attention that youths receive. Confidentiality was described as the most challenging issue when working with this population. 	 Do researchers have an obligation to involve parents or report the findings of studies to them? What do researchers do if other sensitive information about the youths (e.g., abuse) emerges during the interviews? Is anonymous reporting acceptable for discussing these sensitive issues in minors? What are researchers' obligations toward youths involved in suicide research?

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Торіс	Findings	Unaddressed issues
Suicide research in specific cultural groups	 The discussions were focused on the acceptability of psychological autopsies in specific cultural groups. The stigmatization and legal status of suicide in other countries can make individuals reluctant to participate and impose additional hurdles for research approval. Outside researchers can make individuals feel more at ease (i.e., able to speak with a member outside of their community) or more uncomfortable (i.e., suspicious of motive, distrusting). 	 What does suicide signify to members of these cultural groups? What care or services are available to individuals should they feel suicidal? What can or should be done when suicide research reveals larger problems?

Table 4. Role of Researchers in Ensuring Ethical Research Practices

Торіс	Findings	Unaddressed issues
Monitoring negative study outcomes	 Researchers disagreed about the extent to which they were responsible for monitoring negative outcomes in their participants. A lack of guidance on this subject meant that decisions were often based on researchers' subjective opinions. Some articles considered a researcher's background to determine how responsible the researcher was for participants, with sor authors arguing that everyone involved in the research should have a clinical background. It was difficult for researchers who had a clinical background to separate their obligations as researcher from their obligations as a health care professional. 	
How studies were designed	• Researchers' opinions about the morality or acceptability of suicide affected how they designed their study (e.g., whether it involved rescue procedures).	 Guidelines are needed. What is the best way for researchers to indicate their own perspective on suicide? How would this affect the ethical evaluation of the study?

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Table 5. Recommendations and Future Directions for Research

Торіс	Findings
Expanding areas of study	 Using alternative study designs and research approaches could help facilitate advances in suicide research. Work should be done to uncover what services or treatments individuals receive in community settings so that this can be fed into the RCT design.
Overcoming barriers to suicide research	 IRBs and REBs need more education about the harms caused by suicide research. Guidelines for suicide research are needed. Researchers should outline their own positions about suicide because the assumption that suicide is a manifestation of a mental illness means that many ethical issues are overlooked.
Ensuring the well-being of researchers	 There should be opportunities within and outside of research teams for researchers to debrief and explore their emotions related to research. It is important that researchers ensure that they are prepared to handle this type of emotional work.

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