

FEATURE ARTICLE

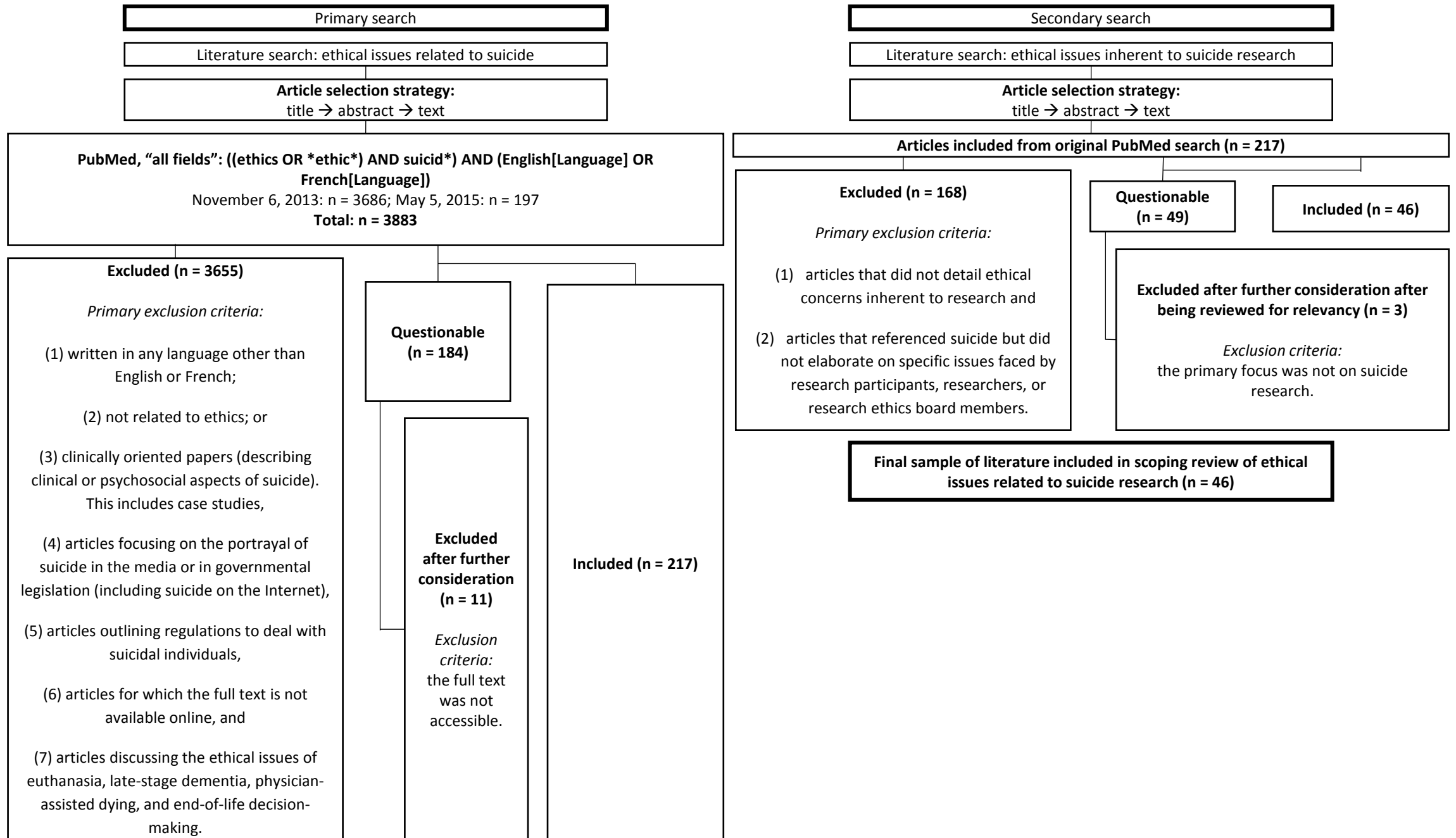
Identifying Gaps in Suicide Research: *A Scoping Review of Ethical Challenges and Proposed Recommendations*

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Figure 1.

Search Strategy to Identify Relevant Articles



randomized controlled trials be done with suicidal youths? *International Review of Psychiatry* 2008;20(2):177-182. **19.** Dolgin E. The ultimate endpoint. *Nature Medicine* 2012;18(2):190-193. **20.** Gold A, Appelbaum PS, Stanley B. Screening for suicidality in the emergency department: When must researchers act to protect subjects' interests? *Archives of Suicide Research* 2011;15(2):140-150. **21.** Shochet IM, O'Gorman JG. Ethical issues in research on adolescent depression and suicidal behaviour. *Australian Psychologist* 1995;30(3):183-186. **22.** Beskow J, Runeson B, Asgard U. Psychological autopsies: Methods and ethics. *Suicide and Life Threatening Behavior* 1990;20(4):307-323. **23.** Cooper J. Ethical issues and their practical application in a psychological autopsy study of suicide. *Journal of Clinical Nursing* 1999;8(4):467-475. **24.** Fisher CB. 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Research participation experiences of informants of suicide and control cases: Taken from a case-control psychological autopsy study of people who died by suicide. *Crisis* 2010;31(5):238-246. **34.** Brown CH, Wyman PA, Brinales JM, et al. The role of randomized trials in testing interventions for the prevention of youth suicide. *International Review of Psychiatry* 2007;19(6):617-631. **35.** Hiriscau IE, Stingelin-Giles N, Stadler C, et al. A right to confidentiality or a duty to disclose? Ethical guidance for conducting prevention research with children and adolescents. *European Child and Adolescent Psychiatry* 2014;23(6):409-416. **36.** Reynolds CF, Degenholtz H, Parker LS, et al. Treatment as usual (TAU) control practices in the PROSPECT Study: Managing the interaction and tension between research design and ethics. *International Journal of Geriatric Psychiatry* 2001;16(6):602-608. **37.** Isometsa ET. 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Table 2.
Issues with Methods Used

<i>Topic</i>	<i>Findings</i>	<i>Unaddressed issues</i>
Psychological autopsy studies	<ul style="list-style-type: none"> • 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. 	<ul style="list-style-type: none"> • 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)	<ul style="list-style-type: none"> • 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. 	<ul style="list-style-type: none"> • 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?

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

<i>Topic</i>	<i>Findings</i>	<i>Unaddressed issues</i>
Vulnerability of research participants	<ul style="list-style-type: none"> • 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. 	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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. 	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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. 	<ul style="list-style-type: none"> • 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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<i>Topic</i>	<i>Findings</i>	<i>Unaddressed issues</i>
Suicide research in specific cultural groups	<ul style="list-style-type: none">• 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).	<ul style="list-style-type: none">• 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

<i>Topic</i>	<i>Findings</i>	<i>Unaddressed issues</i>
Monitoring negative study outcomes	<ul style="list-style-type: none">• 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 some authors arguing that everyone involved in this 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.	<ul style="list-style-type: none">• Should researchers have different obligations toward their participants based on the type of research?• Guidelines are needed.
How studies were designed	<ul style="list-style-type: none">• Researchers' opinions about the morality or acceptability of suicide affected how they designed their study (e.g., whether it involved rescue procedures).	<ul style="list-style-type: none">• 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?

Table 5.
Recommendations and Future Directions for Research

<i>Topic</i>	<i>Findings</i>
Expanding areas of study	<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• 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	<ul style="list-style-type: none">• 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.