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Abstract

Aim: Youth suicide research stands to benefit from involving young people with lived experience as research partners, however there may be a number of barriers to doing this successfully. The aim of this study was to identify the extent to which international youth suicide prevention researchers actively partner with young people in intervention research design, and to explore the barriers, facilitators and benefits to such engagement.

Methods: Ninety-seven eligible researchers were identified using a systematic literature search and invited via email to participate in an online questionnaire.

Results: Only 17 participants (17.5%) at least partially completed the questionnaire, and minimal qualitative data was provided.

Conclusions: Analysis of the limited data together with the low response rate suggest the rate of youth partnerships in suicide prevention intervention research is very low. Guidelines regarding how to safely and effectively partner with young people in this sensitive research area may help to address this gap.

1. Introduction

The importance of involving young people with lived experience as active partners in health research is becoming increasingly recognised, with many policy makers and funding bodies now mandating consumer involvement. As a result, more and more studies are published regarding ways of engaging youth in research and making recommendations for the field (e.g., Bevan Jones et al., 2020; Hawke et al., 2018; Lohmeyer 2020; Tsang, Fletcher, Thompson & Smith, 2020). Benefits to youth partnerships include greater relevance of the research question, improved recruitment and retention rates, better long-term outcomes, and ensuring that interventions and methodologies are youth-friendly (Faithfull, Brophy, Pennell, & Simmons, 2019). Despite these benefits, barriers to youth partnerships in health research have also been identified, related to a lack of knowledge or confidence on the part of researchers as well as resource limitations such as funding, training, and the capacity to provide adequate support to the young people involved (Hawke et al., 2020; Faithfull et al., 2019).

The high rates of youth suicide (Australian Bureau of Statistics, 2019; World Health Organization, 2018) mean that prevention research is increasingly important. Suicide can be a sensitive topic, and therefore there may be additional challenges to engaging youth partners in this type of research. Indeed, to the best of our knowledge, very little suicide research involves young people as active partners. Moreover, little is known about the barriers, facilitators and benefits associated with youth partnerships from the perspective of suicide prevention researchers.

The aim of this study was to identify the extent to which youth suicide prevention researchers actively partner with young people in designing and conducting intervention research, and to explore the barriers, facilitators and potential benefits to such engagement.

2. Methods

2.1. Participants

Eligible participants were first or last authors on published studies evaluating youth suicide prevention interventions. The search strategy for identifying studies was based on that used by our team for a recent systematic review and meta-analysis of youth suicide prevention interventions (Robinson et al., 2018), which we updated for the purpose of this study. In brief, Medline, PsycINFO, and EMBASE were searched in August 2019 using keywords relevant to suicide-related behaviour, intervention type and youth. English language studies published from the year 2000 were included if they: evaluated the impact of an intervention specifically designed to reduce suicide-related

behaviour; assessed a suicide-related outcome; and targeted young people. No restriction was placed on study design. See Robinson et al. (2018) for the search strings used.

2.2. Measures

Participants completed an online purpose-designed Qualtrics questionnaire comprising both multiple choice and open-ended items. Questions asked about organisational systems/support for youth advisors, experiences of partnering with young people in the design of an intervention (including reasons for not doing this), and experiences of partnering with young people in the design of a research project. Participants were also asked to rank 11 possible barriers in order of significance, and to provide free-text responses regarding the barriers, facilitators and benefits to partnering with young people. Participants were able to skip the open-ended and ranking items. The average duration of questionnaire completion was approximately 14 minutes.

2.3. Procedure

Participants were recruited between September and November 2019. All identified eligible researchers were initially invited to participate via a personalised email sent using Qualtrics survey software. Reminder emails were sent via Qualtrics twice more, approximately three weeks apart. To mitigate the risk that the emails automatically sent via Qualtrics were being marked as junk, the final round of recruitment emails was sent from the lead author's institutional email address. In total, eligible researchers were approached up to four times to participate. No monetary incentive was offered.

2.4. Statistical analysis

For quantitative data, simple frequencies and percentages were calculated using IBM SPSS Version 25. We intended to analyse qualitative data using thematic analysis, however due to insufficient data it was determined that no meaningful analysis could be conducted.

2.5. Ethics

The study received ethical approval from the University of Melbourne Human Research Ethics Committee (ID 1954962). All participants provided informed consent prior to beginning the survey.

3. Results

A total of 97 eligible researchers were identified and invited to participate; of these, 18 completed the demographics section of the survey plus at least one other question group (18.6%). One was later removed from analysis because they reported they had never conducted suicide prevention research with young people, leaving 17 participants with data amenable to analysis. Of those 17, only seven (41.1%) answered every question asked of them (i.e., excluding questions displayed based on response to a previous question).

Participants were from the USA (35.3%; $n = 6$), Europe (23.5%; $n = 4$), Canada (11.8%; $n = 2$), New Zealand (11.8%; $n = 2$), and one each (5.9%) from Australia, the United Kingdom and Israel.

Participants had worked for between one and 28 years in suicide prevention research (Mean = 13.2; SD = 7.8), and had conducted between one and ten studies specifically examining suicide prevention interventions for young people (Median = 3 studies).

Almost half the participants (47.1%; $n = 8$) reported that they had never worked for an organisation that had youth advisors. Seven participants (41.1%) indicated they either currently or had previously worked for an organisation with youth advisors, and two (11.8%) indicated that they had not worked for an organisation with youth advisors but that youth advisor involvement with their projects had been facilitated by external stakeholders.

Seven participants (out of 16 who responded to the question; 41.2%) had actively partnered with young people in the design or adaption of a suicide prevention *intervention*, four of whom (57.1%) reported this partnership in the publications related to the project. Only one participant had actively partnered with young people in the design or adaption of a suicide prevention *research project*, and had reported on this in the associated publication.

4. Discussion

This study aimed to examine the extent to which suicide researchers actively partner with young people in the design and delivery of intervention research, and to explore the barriers, facilitators and benefits of partnering with young people for this purpose. Despite a targeted recruitment strategy involving multiple personalised email invitations, only seventeen eligible participants (17.5%) at least partially completed the survey. Moreover, the amount of qualitative (i.e., free text) data provided was minimal and insufficient for analysis.

Analysis of the data received showed that rates of partnering with young people in the sample were low; less than half of respondents had ever actively partnered with young people in the design of an

intervention and only one had engaged young people in study design. Of those who had partnered with young people, just over half had reported on this in the publication(s) arising from the project. Organisational promotion of youth partnerships was also low, with only half of participants reporting they had worked for an organisation with youth advisors who regularly consulted on projects. Given that researchers may have been more likely to answer the survey if they had partnered with young people, the true occurrence of youth partnerships in suicide research may be even lower. Given the increasing emphasis placed on consumer partnerships in research by policy makers and funding bodies (Greenhalgh et al., 2019), it is disappointing that these findings suggest youth suicide prevention researchers are either not partnering with consumers, or not reporting it.

Although the minimal data collected precludes a full understanding of the reasons for this, it is likely that known barriers to youth engagement research more generally apply here too (Faithfull et al., 2019; Hawke et al., 2020), perhaps most significant of all being widespread lack of investment from funding bodies, academic institutions, and individual research teams. Other identified barriers to youth engagement more generally be exacerbated due to the sensitive nature of the topic of suicide prevention. For example, challenges related to accessing young people with lived experience and providing them with adequate support may be particularly pertinent where risk is a concern. Indeed, challenges related to ethics and safety are known barriers in suicide research more generally (Andriessen et al., 2019; Bailey et al., 2020). Given that evidence suggests it is safe to talk to young people about suicide (Blades, Stritzke, Page, & Brown, 2018), suicide prevention researchers should prioritise youth partnerships, and allocate time and budget for these when planning new projects. Research organisations should facilitate these partnerships through the creation of networks of young people with a range of lived experiences, and by ensuring appropriate supports are in place. Additionally, whilst frameworks to guide youth participation in mental health research do exist (Darnay, 2019; Orygen, 2016), to our knowledge no guidance exists for youth suicide research specifically; the development of such guidelines should be a future priority.

The small sample size and low response rate are clear limitations of this study, and it is acknowledged that the findings lack generalisability. The limitations, however, may also suggest a general lack of importance placed on youth partnerships within the suicide prevention sector. Indeed, given the current project employed standard strategies to improve response rates, including repeated reminders, personalised recruitment messages, and a total survey length of less than one thousand words (total length = 754 words) (Phillips, Reddy, & Durning, 2016), the response rate of 17.5% is disappointing.

This is particularly surprising given that another recent study by our team involving a researcher survey which used the same recruitment strategy, including sending up to four reminder emails, returned a response rate of 50 percent (Bailey et al., 2020). Of course, with no data available on researchers who did not respond, it is possible that non-response was due a myriad of other factors including lack of time or emails being marked as junk.

It is acknowledged that researchers are often time-poor and may have difficulty committing time to complete surveys about research practices. To encourage engagement of academic experts in future studies of this nature, we suggest that in addition to the measures already taken by our team (described above) researchers consider offering an incentive for participation and perhaps send more than four follow up emails. When considering the low response rate of this study in the context of comparable research, however, it is likely that the lack of importance placed on this topic by individual researchers, no doubt influenced by factors such as funding and institutional support as well as the lack of emphasis placed on the topic by many scientific journals, may have had the most impact on their reluctance participate in this research project. Repeating this study in a few years' time may provide an indication of whether or not this has changed.

5. Conclusion

This study suggests rates of youth partnerships in youth suicide prevention research are low, although more research is required to confirm this and to explore the benefits, facilitators and barriers to these from the perspective of both researchers and young people. There is a need for guidance on how to safely partner with consumers in youth suicide prevention research, including recommendations for reporting and evaluating this process. More pertinently, there is a need for dedicated investment and support from funding bodies and academic institutions, as well as active and visible promotion of youth partnerships by international research societies and associations. Additionally, journals should consider requiring authors to submit a statement of consumer participation with their manuscript, as is becoming increasingly custom for funding bodies.

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Conflict of interest statement

The authors declare no conflict of interest.

Data availability statement

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

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