Ethical issues arising in research with people with mental health conditions

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Case study
Co-developing communication activities for a community-based trial on suicide prevention, India

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Background and a brief description of the research project
India accounts for 33% of all suicides worldwide. The number of deaths due to suicide is highest amongst young adults, aged 18 to 45 years.[1] In 2013, the nationally representative *Million Death Study* estimated that the rate of death by self-poisoning was 7.9 per 100,000 per year for women and 13.8 per 100,000 per year for men, with pesticide consumption being a major means. Unlike high-income countries where 90% of the cases have a concomitant mental health diagnosis, in India, suicides are often caused by an interplay of various health and socio-economic factors, including physical impairment, chronic pain, poverty, debt, and gender-based violence.[2]

The United Nation's *Sustainable Development Goals* seek to reduce global suicide rates by one-third in the next decade under target 3.4.2 which adds towards the fulfilment of Goal 3 to ensure healthy lives and well-being promotion.[3] However, achieving this target requires a scalable and comprehensive approach, given the multifactorial causality of suicide in India. In the *Suicide Prevention and Implementation Research Initiative* (SPIRIT), a cluster-randomised trial, we will implement an integrated set of three evidence-based interventions (a) to reduce suicidal ideation among adolescents (b) to reduce access to pesticides as a means of self-poisoning and (c) to train community health workers to recognise and provide support to those at risk of suicide. Using the RE-AIM Framework, SPIRIT also studies the implementation of these interventions across 116 villages of Mehsana, Gujarat, to identify the key factors that help or hinder effectiveness and sustainability.

One of the SPIRIT interventions encourages farming households to store their pesticides at a community storage facility (CSF) in the village to limit their access to means, which is a recommended and feasible method for preventing suicides.[4] To co-develop strategies for improving its uptake, multiple focus group discussions were conducted with the managers of the CSFs and the community members who had already registered for the facility (registrants).

Amongst other questions, the registrants were asked their opinion of the communication activities undertaken for raising awareness about the CSFs. These activities included: posters; door-to-door visits; a booklet and pamphlets; and a theatre campaign. Below are the main learnings from the discussion.

Ethical issues with commentary on each issue

A. The focussed group discussions with community members to improve uptake suggested use of fear as a motivator. The participants suggested that any print materials for the promotion of the intervention should have images that explicitly show suicide as the dire consequence of not storing one's pesticides at the CSF. They insisted on using graphics that depict the direct implications of using this preventive strategy like showing imagery of a child's death due to consumption of pesticide due to its easy access. In India, their prior experience of engagement with various public sphere health communication for behavioural change uses fear like gruesome images of cancer pathology on cigarettes packets. Such practices of using threat appeals, fear evoking persuasive

imagery, has been widely used to disseminate information across a wide variety of topics (e.g., HIV/AIDS, cancer, occupational safety).[5] Bringing in the same inclination to suicide prevention however can be triggering and risky with individuals at varying risk modalities might interpret it differently, culminating in unintended repercussions up to increased likelihood of suicide particularly in individuals with known depressive or suicidal symptoms.[6,8] Besides such messaging often leads to normalizing or sensationalizing suicide among exposed non-target groups.[6,7] Though our proposed sub-intervention requires a new visual syntax that is easily understood by the community and championed by them, incorporating their suggestion risks contradicting the core ethic of "nonmaleficence"- doing no harm in research.

B. The sub-intervention aims to measure the reach of communication activities like theatre campaign at centralized spots in the village. Similarly, it relies on the mainstream gatekeepers for adaptation and contextualization of various aspects of the intervention implementation. Such an approach inadvertently excludes the marginalised groups often inhabiting the outskirts of the village and isolated from the centre. A suggested remedial targeted approach is disrupted by their reluctancy to participate in such participatory activities. The fear of stigma, feeling of shame and loss of pride associated with suicide unwittingly exclude those with lived experience of suicide who typically maintain a low social profile. Any targeted approach for dissemination on one hand ensures the representation of true experience of people with lived experience, but on the other hand it can undermine the statistical power of the quantitative study's results and thus risk the generalizability of results for such large scale-up studies. Besides it could also lead to further stigmatization of such groups and communities by the mere assumption that since they are more prone to such risky behaviour it might normalise the increasing trend with the community, or it may also sensationalise the incidence of suicide among them.

Conclusions and recommendations

1. The concern for ethical language should extend to visuals too and when the research team works with the community to co-create content, they should equally consider the aesthetic appeal, clarity, and semiotic charge of any image option with clearly defined boundaries around incorporation of suggested matter. Given that the facilitator and the participants may not have a common background, effectively debating the latent meanings of a picture may require its own set of tools and skills. Such processes should intend to nurture the awareness of the community participants and to empower them to grasp the nuances around the sensitivity of the subject matter so to enhance their participation in productive manner within the ethical bounds. Such discussions are crucial particularly for multicausal issues like suicide where stereotypical thinking and myths are anyway rife.

2. A stratified approach can be taken to define the outcomes of various promotional exercises, where the issue being addressed does not directly affect the majority, yet collective action is imperative to preventing illness, deaths or disability. A subset of objectives can be created to focus on the most vulnerable within the larger goal still focussed on influencing attitudes or behaviour at a community level. This might include assured participation or representation from these subsections but should not be limited to them solely so to avoid privacy issues that may fuel up the stigma attached with such a targeted approach. Suggested approach would ensure that the margins and the mainstream are systematically represented at all stages of work from co-creating material to dissemination.

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