

Ethical issues arising in research with people with mental health conditions

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Case study: Research ethics in an epidemiological study of adolescent mental health in Mexico

PhD. Pamela Garbus, Psychology Department, Universidad Autónoma de Querétaro (Autonomous University of Querétaro), Mexico

Description of the research project

This was a cross-sectional, epidemiological-observational study that sought to describe the prevalence of depressive symptomatology, suicidal ideation and attempt, and drug use in public high school students in two municipalities in the state of Querétaro, Mexico. We sought to determine whether certain psychological and psychosocial factors such as self-esteem, locus of control, impulsivity, coping response to family stress and everyday social stress, the relationship of the adolescent with his or her father and mother, and support resources and socio-demographic data would have a predictive relationship with the mental health variables investigated.

The sampling was stratified, two-stage and by conglomerates. The stratification variable was the level of marginalization of the area in which the school was located. The first stage consisted of the selection of the schools and the second of the groups of students within them. Participation was voluntary, with parental permission and consent of the participants.

A self-administered questionnaire was used, consisting of different standardized and validated scales for the Mexican population. We found a high prevalence of recent suicidal ideation, current suicidal ideation and suicidal behaviour, as well as a significant predictive relationship with risk factors for depression, impulsivity, locus of internal control, alcohol, marijuana and inhalant consumption, economic problems and protective factors, self-esteem, and supportive resources.

This confirms the importance and urgency of carrying out specific actions around the promotion, prevention and care of suicidal problems in the region. With the results obtained, a workshop was held with secondary school teachers, which sought to encourage the identification, timely attention and channelling of the problems prevalent with this population. It is expected that this workshop will be replicated in the region. The results were shared with the state education authority, with whom agreements were established to continue researching and contributing to the resolution of this problem.

Background

There is a close relationship between mental health problems and conditions of social vulnerability. On the one hand, mental disorders produce great costs to families, on the other hand, conditions of poverty, violence and lack of opportunities during childhood and adolescence increase the probability of developing this type of disorder (WHO, 2016). This is alarming considering that 1 out of every 2 children and adolescents in Mexico lives in poverty; of these, 20% are in extreme poverty.

Despite the seriousness of the mental health situation of children and adolescents, there are few studies on the prevalence of this problem that use social impact as an indicator of ethical concern in Mexico.

In Mexico, mental disorders have much earlier onset ages than in other countries (Aguilar-Gaxiola & Deeb-Sossa, 2009). According to the Mexican Ministry of Health, in the years 2013-2018, 24.7% of the adolescent population was affected by one or more mental health conditions, depression being one of the main ones.

With regard to suicide, the suicide rate in Mexico has been increasing and is associated with an increase in social unrest; from 2000 to 2014, the suicide rate rose from 3.5 to 5.2 per 100,000 inhabitants; eight out of 10 suicides (80.02%), 40.2% of suicide cases were treated in young people between 15 and 29 years of age, the rate in this population being 7.9 suicides per 100,000 young people. In Querétaro the suicide rate in 2014 was 3.9 per 100,000; in the population aged 15 to 29 the rate is much higher, 5.6 per 100,000 (INEGI, 2016). It has increased in individuals over 10 years of age in recent years.

The figures for alcohol consumption in Mexico are on the rise. Alcohol is responsible for 6.5% of premature deaths and 1.5% of the days lived in poor health. 41.9% of boys and 39.4% of girls in secondary schools have consumed alcohol at some time in their lives, and the percentage of secondary school students who have drunk excessively was 14.5%. Notably, in primary schools about 17% of the student population reported having tried alcohol and 2.4% of students reported heavy drinking (Salud, 2017b).

Ethical issues

Maximising impactful, locally-relevant research

Relevant and ethical research with a local perspective and social impact can be maximised through the involvement of decision makers, in this case education and mental health. For this reason, during the design of the research, the state education authority was called upon to advance the proposal. Likewise, support was requested from the State Centre for Mental Health, to design the action plan to be followed in the event that a participant experienced a crisis or needed immediate attention.

The topic addressed is relevant to investigate from the design of epidemiological studies, with a strong local component that seeks to impact on improving the mental health conditions of adolescents. The training and subsequent involvement of undergraduate and graduate students in research teams in studies of this type is feasible and relevant, since it does not involve a psychopathological, specialized, and individual assessment of each participant in the study.

Engagement and co-creation

Who else should be involved during the design and implementation of the research (e.g., caregivers, local communities, young people, etcetera.), how and for what purpose (e.g., establishing priority issues to explore, informing the design and conduct of the research, as part of a campaign against stigma, etcetera)?

Decision-makers, in this case in education and mental health, must be called upon from the beginning of the study design not only to obtain full access to the institutions and the study population, but also to have the results obtained as input into their care practices for the specific population. In this case, the collaboration of the middle management in education in each municipality facilitated the opening and support of the school directors. The transfer of the results to the decision-makers made it possible to establish actions between the team and the state education authority to work between sectors and detect the prevalent problems.

Capacity

We must advocate for the rights of adolescents to participate in bodies that take into consideration situations that especially concern them, such as their mental health. During the informed consent process, we encountered an obstacle since more parents than expected did not authorize their children's participation, even when the child expressed their assent.

This was despite the fact that this was a study that represented only a minimal risk, considering that it involved answering a standardized, self-administered and anonymous questionnaire and that it did not consist of a psychiatric or psychological evaluation, but rather, by the nature of the study, was a screening instrument. This led us to reflect on a very relevant aspect in mental health research and especially with adolescents: respect for the principle of autonomy.

The invitation to participate in this type of study can promote autonomy, a capacity that develops precisely from the demand of the social context. Work needs to be done during the consent process with parents and guardians to reduce the stigma of mental health problems and to encourage the autonomous participation of adolescents. Organized activities such as workshops with them could help.

Conclusions and recommendations

Mexico is a middle-income country with high inequality. It is also a country with high prevalence rates of mental health problems with an increasingly early onset.

Encouraging studies on Latin America adolescent mental health, in a social setting with high rates of violence is extremely necessary. Ethical epidemiological research, with a local focus, on mental health issues with adolescents in such adverse contexts, should be a priority for researchers, funders and decision makers, especially those whose goal is that their results are inputs for the design of specific actions for their improvement. To achieve this, it is recommended:

-Convene decision makers from the beginning of the investigative process.

Encouraging the participation of this very specific population is a challenge for the ethics of scientific research. It is very necessary to promote mental health studies in a group whose ability to make decisions is being questioned, including studies involving the development of ethical knowledge about the characteristics and implications of their participation.

This is why it is recommended:

-That studies incorporate into their procedures the necessary time so that the information provided during the invitation to participate guarantees an autonomous acceptance or refusal by the adolescents. Letting them know that their opinion counts promotes the development of the capacity for autonomy. Parents and guardians should also be invited to reflect on the benefits of their children's participation. They should be especially concerned about the stigma and burden of mental health problems that make them unwilling to share information about their children, even anonymously.

References

- Aguilar-Gaxiola, S. A., & Debb-Sossa, N. (2009). La investigación en epidemiología psiquiátrica y la Encuesta Mundial de Salud Mental de la Organización Mundial de la Salud en América Latina y el Caribe. *En: Rodríguez J., Kohn R., Aguilar-Gaxiola SA, editors. Epidemiología de la salud mental en Latinoamérica y el Caribe. Washington, DC: PAHO (Organización Panamericana de la Salud), 35-53.*
- INEGI. (2016). *Estadística a propósito del Día mundial para la prevención del suicidio* (10 de septiembre). http://www.inegi.org.mx/saladeprensa/aproposito/2016/suicidio2016_0.pdf
- Instituto Nacional de Psiquiatría Ramón de la Fuente Muñiz, Instituto Nacional de Salud Pública, Secretaría de Salud. *Encuesta Nacional de Consumo de Drogas, Alcohol y Tabaco*

2016-2017: *Reporte de Tabaco. México: INPRFM*, 2017.

https://encuestas.insp.mx/ena/encodat2017/encodat_tabaco_2016_2017.pdf

- WHO. (2016). *Adolescentes: riesgos para la salud y soluciones*.
<http://www.who.int/mediacentre/factsheets/fs345/es/>