Key informants in socio-epidemiology: advantages and pitfalls

SARAH O'NEILL | ISABELLE GODIN
École de Santé Publique, Université Libre de Bruxelles, Bruxelles, Belgium.

This commentary is on the original article by Jahan et al. To view this paper visit https://doi.org/10.1111/dmcn.14616

When undertaking a cross-sectional, population-based epidemiological study to describe the characteristics of affected individuals, it is crucial that the right individuals are selected for clinical examination. Epidemiologists have gone about this in different ways. Some clinically examine and recruit identified patients in the field. However, this approach is time-consuming and costly as clinicians have to spend extended periods of time examining individuals whose symptoms are not necessarily relevant to the study objectives. The key informant method was originally developed in anthropology to gain in-depth insight into particular social contexts by working with locals who have the ability to explain and 'translate' social phenomena, cultural values, and behaviours.[1] This method has been adapted for epidemiological surveys as outlined by Jahan et al. and is certainly attractive for population based studies as it relies on the knowledge and networks of local people.[2] Unfortunately, few details are provided on the training of the key informants. Of course good communication skills with locals are important, as well as being able to identify particular individuals with clinical symptoms or characteristics at community level – as is the case when using socio-anthropological and community-based approaches in epidemiology.

Another important factor relevant to the identification of study participants is how stigma associated with disability might affect recruitment. Stigma associated with epilepsy and other disabilities has been extensively researched and studies show that affected children are frequently not sent to school, primarily because teachers in low-resource settings have difficulties addressing their needs. Another reason for school drop-outs or non-attendance is that children, particularly those with visible disabilities, are commonly teased, ostracized, and rejected by peers. Sometimes it is believed that the condition is infectious and peers, teachers, and even health professionals show avoidance behaviour to protect themselves from 'catching' the condition themselves.[3] Other studies have described cultural beliefs about disability being caused by witchcraft or a divine punishment for immoral behaviour.[4] The caregivers of children with conditions such as CP thus often have a double responsibility: adequately taking care of the needs of the child as well as dealing with stigma associated with the condition. The burden is thus not merely financial (i.e. being able to address a child's physical and developmental needs), it is also psychological (how to shoulder cultural beliefs and local aetiologies regarding the cause of the condition and how to pre-empt avoidance behaviour resulting from stigma). For some conditions, such as epilepsy, it has also been shown that parents may hide severely affected children to avoid stigma.[2,3] In such cases, children may be severely neglected, malnourished, and even sexually abused.

In the paper by Jahan et al., we do not know if and how stigma associated with CP was addressed; for instance, whether caregivers may have hidden children with motor deficiencies from the community to avoid stigma. How were such situations handled by key informants? These methodological aspects also have ethical implications.[4] Once children with conditions like CP are identified and recruited it is crucial to address how children's needs – including coping with stigma – are addressed after the study has been completed. Epidemiological studies of individuals with neurological disorders can have the adverse effect of rendering their living conditions and social lives more difficult due to stigma. The training of key informants should therefore cover clinical and epidemiological aspects, but also provide a solid ethical framework (including sensitivity) when communicating with and recruiting vulnerable groups so as not to induce undesirable consequences within their communities.

REFERENCES

1. Bernard HR. Research Methods in Anthropology: Qualitative and Quantitative Approaches (4th Edition). Lanham, MD: Altamira Press, 2006.

2. Jahan I, Al Imam MH, Karim T, et al. Epidemiology of cerebral palsy in Sumba Island, Indonesia. *Dev Med Child Neurol.* 2020. https://doi.org/10.1111/dmcn.14616.

3. O'Neill S, Irani J, Siewe Fodjo JN, et al. Stigma and epilepsy in onchocerciasis-endemic regions in Africa: A review and recommendations from the onchocerciasis-associated epilepsy working group. *Infect Dis Poverty.* 2019; **8**(1): 1–11.

4. Irani J, Rujumba J, Mwaka AD, et al. "Those who died are the ones that are cured". Walking the political tightrope of nodding syndrome in northern Uganda: Emerging challenges for research and policy. *PLoS Negl Trop Dis.* 2019; **13**(6): 1–18.