

is the responsibility of the school authorities to ensure that children have access to safe drinking water throughout the school hours.

Questions

1. What are the ethical issues at stake here?
2. What is the ethical responsibility of the researcher in this situation?
3. Will the researcher's ethical responsibilities be different if she is studying the availability of safe drinking water to school children?
4. What are the researcher's responsibilities when she finds out that ancillary findings contradict government reports?
5. What are the researcher's responsibilities when media reports question the availability of safe drinking water in schools and the media demands a government level enquiry and action?

Unanticipated challenges: Institutional anonymity vs child health

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Background

The case study presented by the researcher reflects on a dilemma faced during her public health research in a setting in South India (1). Her case prompts discussions around the public health context, ethical dilemmas therein, research challenges and relevance to other situations in public health research.

The public health context of the case study

The ethical dilemma concerning ancillary or incidental findings and the appropriate care options and obligations have been recognised and articulated in the literature. Incidental findings are defined as those concerning an individual research participant that have potential health or reproductive importance, and are discovered during the course of conducting research but are beyond the aims of the study (2). Most of the accounts regarding incidental findings in the literature are about dealing with individual level ancillary findings. In contrast to these, public health research targets communities, populations, institutions and larger geographical areas (3). In such public health studies, ancillary findings do pose ethical dilemmas such as the one faced by the researcher while examining the effectiveness of oral health education on the oral hygiene status of school children within the context of the school health programme in a southern Indian setting (1).

Ethical dilemmas highlighted by the case study

The interesting case study presented by Neethu Suresh (1) highlights ethical dilemmas faced by fellow public health researchers. One such dilemma is maintaining the confidentiality of the institutions studied. In her case, the institutions that did not have the provision of safe drinking water could have been identified. This could be in breach of the confidentiality clause, if stated in the informed consent process.

Further, making such information available in the public domain can give rise to challenges for the schools and further for their community.

A second issue of concern is that of the safety and well-being of the children in the research study and of those similarly situated. It is imperative that safe drinking water is provided and as such the investigator has to find a way to discuss with the teachers the anonymising of the institution's deficiency on that account, and the possibility of communicating it to the relevant departments or stakeholders.

Discussion

Case study specific challenges

The case study highlights the methodological challenge of how to mask the identity of study units so that researchers can maintain confidentiality while disclosing their findings for remedial action. In the context of studies based on individuals, it may be possible to consider using masking methods while selecting participants (sampling methods), or assigning interventions (randomisation), or use of a group approach (such as medical camps) for collecting data. However, it is difficult to implement such methods for group or population-based studies.

The designing of studies to anonymise group level information poses a challenge. However, at the protocol stage, the public health researcher needs to have anticipated that safe drinking water is a variable concerned with the research question

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and analysis plan. Such foresight could have helped the researcher to take care of such issues at the consent stage, and in anonymising the institution findings while reporting or communicating findings. This can protect the confidentiality of the institution.

Needless to say, provision of safe water is not directly linked to the health sector handling the school health programme. However, as a public health researcher, whether in the context of research question or analysis plan, the provision of safe drinking water, is indeed a related variable. Whether this was anticipated by the researcher or not, such an ancillary finding needs to be addressed. It is necessary for the researcher to communicate the need to provide safe drinking water to the concerned departments, such as the public works department. It may also be possible to raise the matter with bodies existing within the schools (such as a parent-teacher association) during de-briefing, while maintaining the anonymity of the concerned institutions

Applicability and relevance to similar situation in public health research

Any public health study dealing with groups may pose such dilemmas. For instance, any such population-based observational (eg, screening for tuberculosis or refractory errors; evaluations) or intervention studies may face ethical dilemmas because of ancillary findings. These may demand action at the individual or group level. Such action may well be within the health domain (eg, clinical or preventive care services) or fall entirely outside the health sector (eg, infrastructure development). The moral resolutions may not vary with reference to research objectives.

Recommendations

In the context of this case study, the researcher has to communicate the findings urgently, as the children's health is paramount. However, since this ethical challenge had not been anticipated earlier, the researcher can discuss the health implications of unsafe water with the teachers, and seek their opinion on how to convey such information to the relevant authorities while maintaining institutional anonymity.

Some general lessons can be learnt from this case study, for other studies involving groups.. In such public health research, the investigators have to anticipate and frame a list of options to deal with any ancillary findings. They need to foresee all the related key variables at the planning stage of the study itself. Such key variables can be considered from research-specific or study setting specific perspectives. The researchers may then define the scope of handling such anticipated options and think of all the sectors involved and the convergence within and between them.

References

1. Suresh N. Ancillary findings during public health research: A researcher's ethical dilemma, *Indian J Med Ethics*. 2020 Jan-Mar;5(1) NS:22-3. DOI: 10.20529/IJME.2020.13..
2. Wolf SM, Lawrenz FP, Nelson CA, Kahn JP, Cho MK, Clayton EW, et al. Managing incidental findings in human subjects research: analysis and recommendations. *J Law Med Ethics*. 2008 Summer;36(2):219–48. doi: 10.1111/j.1748-720X.2008.00266.x.
3. Hyder AA, Merritt MW. Ancillary care for public health research in developing countries. *JAMA*. 2009 Jul 22;302(4):429–431. doi:10.1001/jama.2009.1072

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