

To Study or Not to Study

Dr AA walked into the tea room looking pensive. “I just saw a six year old boy complaining of burning urination and a rash on his groin. I suspect he has syphilis and this is the fourth case of a sexually transmitted disease (STD) that I have seen in the last two months. The other three were also boys of approximately the same age group from 6–8 year old.”

“Are these patients related to one another?” I asked.

“No, they’re not related but they come from the same community where I see other patients with STDs. That is why I am even more concerned and have come to you for advice since you are an epidemiologist with expertise in public health research and have an interest in bioethics. I feel that this community needs to be researched to discover if harmful sexual practices are prevalent there so that we can help them. I have some ideas and concerns that I want to bounce off you before I write my research proposal.”

“How can I help?” I asked.

“I tried to look for a common thread among the five cases I have seen until now,” replied AA. “They are all young boys not related to one another and the contacts they have mentioned are different people.”

“Are they going to the same school or religious seminary?” I asked.

“No, I checked that as well. The only common thread was the community to which they belong. It is located on the outskirts of the main city and the population is roughly 40,000,” reported AA. “As I mentioned, I have mostly seen adult men from that community with STDs. I know that some of them are commercial sex workers, but a few others are involved in homosexual practices for the gratification. I fear that young boys are being molested or may be inducted into their social group.”

“Are you sure that they are not homeless street children, since we know for a fact that they tend to get involved in dangerous sexual practices?” I asked.

“No, I rechecked my notes and they come from middle class families. They were brought in by concerned family members.”

“OK, now tell me. What do you want to study?” I asked, donning my epidemiology cap. “And why do you want to do so?”

AA responded, “I want to study sexual practice patterns in this community among all age groups. Based on that information, we can then devise an intervention like educational programmes for the community. I think it is our collective responsibility to this community.”

“Then educate,” I responded. “Spread pamphlets, talk to schools and use other social forums.”

“How can we plan an intervention when we are not sure what the practices are?” AA asked. “We need to know the ground realities before any intervention or we will risk getting thrown out from that community.”

“Okay,” I replied. “Suppose you start the study and they *do* throw you out, or not let you in to do the study in the first place. What would happen then?”

“I suppose instead of doing any good, we may end up being the bad guys,” admitted AA. “We may lose the confidence of the people who come to our hospital.”

“Then I will ask you, is the study worth the risk?” I responded.

“Of course it is,” replied AA. “I can’t claim a scientific conclusion based on the few cases that I have seen.”

“If the study is indeed essential to perform, are we the best ones to do it?” I asked, examining the problem from another angle. “Is it not prudent to involve an NGO or a government agency to do it?”

“I think it is our responsibility to carry out the study,” retorted AA. “We see patients from that community. These patients keep our hospital running. These patients also accommodate our students in their learning. Don’t we have any responsibility towards them?”

“And involving an NGO or the government would mean that the community will have to be identified. Would there not be a risk of stigmatizing the community?” AA added. “I may be asked to identify my index cases. Can there be any justification for doing so?”

“I guess it could be justified if the intention is to do greater good for the community,” I responded. “And please keep in mind, if you intend to intervene based on your findings, the community will automatically be identified.”

“You are right,” said AA. “Even with greater good in mind, the target population will still have to be identified, and they may not take kindly to this, which is why I am considering dropping the idea of identifying the community altogether.”

“If you choose to keep the community under wraps, how do you intend to carry out any remedial interventions?” I asked. “What is the use of this study?”

AA was at a loss for words. He is convinced that the study needs to be done but the proposal has yet to be written.

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