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Objective monitoring of mosquito bednet usage and the ethical challenge of respecting study bystanders' privacy

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Abstract

Insecticide-treated bednets are among the most prevalent and cost-effective tools for preventing malaria throughout the world. Consistent bednet use is crucial for effectiveness, but assessing adherence is challenging due to limitations in current measurement tools. Recent technologies have introduced methods for remote electronic bednet use monitoring. While valuable for researchers, these monitoring tools create potential ethical concerns for study bystanders because the monitors are typically unable to discriminate between individuals who are or are not study participants. Considerations related to study bystanders, including privacy, ancillary care obligations, and community perceptions, are discussed.

Keywords

Bystander privacy; ancillary care obligations; community perceptions; bednets; malaria prevention; adherence monitoring

Insecticide-treated bednets are among the most prevalent and cost-effective tools for preventing malaria and are recommended for the 3.2 billion people worldwide at risk for malaria.[1–3] Bednets are unfurled during sleeping hours to provide a barrier against mosquitoes that spread malaria, and insecticides embedded in the netting kill mosquitoes to prevent spread of the infection to others. Ensuring that bednets are used consistently is a crucial component of malaria control programs.[4]

Accurate measurement of bednet use is required for designing optimal malaria prevention programs, but assessing adherence to bednets is challenging. The most common method consists of periodic self-reports, which tend to overestimate use because of social desirability and recall bias.[13] Other techniques, such as unannounced night visits to confirm actual use, suffer from acceptability and logistical challenges. Recent technological advances have enabled remote electronic monitoring of bednet use, similar to tools used

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to measure medication adherence.[5] Methods using electronic sensors embedded in bednets, or placed around the sleeping area, to create a record of bednet use have been deployed in pilot studies[6–8] and are now being utilized in larger research studies proposed for research.[14] Newer advances, not yet deployed, might use proximity sensors, video recording, or geolocating tags to track not only when a bednet is unfurled but also who is under the bednet. These technologies would aid in quantifying individual-level bednet protection and help in more precisely associating bednet coverage with malaria outcomes. These new research tools could enhance researchers' abilities to address previously unanswered questions about how bednet use impacts clinical disease, infectivity, and mosquito behaviors.

As measurement tools for bednet use are employed, a variety of ethical concerns arise, particularly for the more advanced technologies. Of most relevance, bednet monitoring tools currently lack the ability to discriminate between individuals who are consenting research subjects and "bystanders"—non-subjects who are nevertheless affected by the study. The potential exposure of bystanders raises concerns about privacy, ancillary care obligations, and community perceptions of bednet monitors.

Privacy

In principle, all permanent household members could be approached for informed consent of bednet use. In practice, however, household composition may be fluid, particularly in resource-limited settings where malaria is common.[9,10] Visitors, including sexual partners, may be transient. Simply recording whether the bednet is or is not in use may pose few risks to a bystander; however, technologies that track individual bednet use (i.e. video monitoring or tracking devices) may result in unintended data gathering without bystanders' consent or even knowledge that data is being gathered. In our recent study in Uganda, for example, video recording was not pursued because of not only concerns about protections for the participants, even given their ability to consent, but also because of particular concerns about recording of unsuspecting bystanders.

Privacy rights of bystanders are affected by two key factors: monitoring location and data sensitivity. Regarding monitoring location, electronic bednet monitors collect data in bedrooms, which are sensitive because of the normative presumption of privacy during sleep and with sexual behaviors. Even when the monitor only detects whether the bednet is up or down, participants in qualitative studies have expressed concerns about the sensitivity of the location.[6] Video recording would surely produce even more trepidation.

In addition, the nature of the data collected by bednet monitors could also present an ethical risk for bystanders. For example, proximity monitors may track the number of bodies in a bed. Even without images, these data could be highly sensitive for a partner jealous about potential infidelity. Low-risk data (i.e. bednet use) can thus be transformed into potentially high-risk data, especially if the data are susceptible to access by non-study personnel.

Ancillary care obligations

Some have argued that research subjects in health-related studies should have rights to ancillary care.[11] Do researchers have an obligation to intervene if, for example, monitors detect bednet non-adherence by bystanders that could place them at risk for malaria?

In addition, with technologically sophisticated monitors, behaviors other than bednet use may be recorded that potentially create an ethical obligation to act. For instance, in a recent study, a domestic altercation was proffered as the reason a bednet monitor was damaged. If video had been gathered, a crime could have been witnessed and legal follow-up may have been necessary. Other examples could include recording instances of theft, child abuse, or rape.

Overall perceptions of bednet monitoring in the community

Beyond individuals, consideration is also necessary for broader community perceptions of researchers' intentions. If households in a village, for example, are "wired" to record bednet use, the entire community may count as bystanders subject to the aforementioned risks. Informing communities collectively about their potential for unintentional study participation is of particular importance in settings, such as rural Uganda, where overtones of colonialism and other north–south power differentials may affect relationships between researchers and communities. Researchers can avoid some of these concerns through engagement of community advisory boards and community-based participatory research methods.[12]

Conclusion

New technologies for monitoring anti-malaria bednet use hold great potential for improving malaria prevention. However, these potential benefits need to be weighed against ethical concerns, including those about bystanders. Of particular relevance are issues of privacy, ancillary care obligations, and overall community perceptions.

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References

1. Lim SS, Fullman N, Stokes A, et al. Net benefits: a multicountry analysis of observational data examining associations between insecticide-treated mosquito nets and health outcomes. PLoS Med 2011; 8(9): e1001091. [PubMed: 21909249]
2. Bhatt S, Weiss DJ, Cameron E, et al. The effect of malaria control on Plasmodium falciparum in Africa between 2000 and 2015. Nature 2015; 526(7572): 207–211. [PubMed: 26375008]
3. World Health Organization. Insecticide-treated mosquito nets: a WHO position statement. Geneva: World Health Organization, 2007.
4. World Health Organization. World malaria report Geneva: World Health Organization, 2016.

5. Campbell JI, Eyal N, Musiimenta A, et al. Ethical questions in medical electronic adherence monitoring. J Gen Intern Med 2016; 31(3): 338–342. [PubMed: 26358284]
6. Koudou BG, Malone D and Hemingway J. The use of motion detectors to estimate net usage by householders, in relation to mosquito density in central Cote d'Ivoire: preliminary results. Parasit Vectors 2014; 7: 96. [PubMed: 24602353]
7. Krezanoski PJ, Santorino D, Nambogo N, et al. Maternal attitudes about objectively monitored bednet use in rural Uganda. Malar Res Treat 2016; 2016: 8727131. [PubMed: 27840766]
8. Krezanoski PJ, Campbell JI, Santorino D, et al. Objective monitoring of insecticide-treated bednet use to improve malaria prevention: SmartNet development and validation. PLoS One 2017; 12(2): e0168116. [PubMed: 28158233]
9. Hosegood V and Timaeus IM. Household composition and dynamics in KwaZulu Natal, South Africa: mirroring social reality in longitudinal data collection. In: Van De Walle E (ed.) African households: censuses and surveys. New York: Routledge, 2015, pp. 58–77.
10. Slesinger DP. Rapid changes in household composition among low income mothers. Fam Rel 1980; 29(2): 221–228.
11. Richardson HS, Eyal N, Campbell JI, et al. When ancillary care clashes with study aims. N Engl J Med 2017; 377: 1213–1215. [PubMed: 28953445]
12. Horowitz CR, Robinson M and Seifer S. Community-based participatory research from the margin to the mainstream: are researchers prepared. Circulation 2009; 119(19): 2633–2642. [PubMed: 19451365]
13. Krezanoski PJ, Bangsberg DR, Tsai AC. Quantifying bias in measuring insecticide-treated bednet use: meta-analysis of self-reported vs objectively measured adherence. J Glob Health. 2018 Jun; 8(1): 010411. [PubMed: 29619211]
14. Krezanoski PJ, Santorino D, Agaba A, Dorsey G, Bangseberg DR, Carroll RW. How Are Insecticide-Treated Bednets Used in Ugandan Households? A Comprehensive Characterization of Bednet Adherence Using a Remote Monitor. Am J Trop Med Hyg. 2019 Jul 8. doi: 10.4269/ajtmh.19-0032