The Cholera Phone: Diarrheal Disease Surveillance by Mobile Phone in Bangladesh

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Abstract. Existing methodologies to record diarrheal disease incidence in households have limitations due to a high-episode recall error outside a 48-hour window. Our objective was to use mobile phones for reporting diarrheal episodes in households to provide real-time incidence data with minimum resource consumption and low recall error. From June 2014 to June 2015, we enrolled 417 low-income households in Dhaka, Bangladesh, and asked them to report diarrheal episodes to a call center. A team of data collectors then visited persons reporting the episode to collect data. In addition, each month, the team conducted in-home surveys on diarrhea incidence for a preceding 48-hour period. The mobile phone surveillance reported an incidence of 0.16 cases per person-year (95% CI: 0.13–0.19), with 117 reported diarrhea cases, and the routine in-home survey detected an incidence of 0.33 cases per person-year (95% CI: 0.18–0.60), the incidence rate ratio was 2.11 (95% CI: 1.08–3.78). During focus group discussions, participants reported a lack in motivation to report diarrhea by phone because of the absence of provision of intervening treatment following reporting. Mobile phone technology can provide a unique tool for real-time disease reporting. The phone surveillance in this study reported a lower incidence of diarrhea than an in-home survey, possibly because of the absence of intervention and, therefore, a perceived lack of incentive to report. However, this study reports the untapped potential of mobile phones in monitoring infectious disease incidence in a low-income setting.

INTRODUCTION

An estimated 1.7 billion children suffer from diarrheal diseases worldwide and an estimated 498,900 children die of diarrheal disease each year.^{1,2} However, these estimates may underestimate the true burden of disease because they rely on surveillance data which typically only capture the number of severely unwell patients presenting to health-care facilities. This is particularly true for low- and middle-income countries, where centralized disease surveillance systems may be lacking.³ Studies that rely on data from hospitals may therefore underreport incidence from mild to moderate, non-hospitalized diarrhea cases. These missed figures are estimated to constitute 65–95% of all diarrhea episodes in low-income areas.⁴ In low- and middle-income countries such as Bangladesh, underreporting of disease incidence can have a significant effect on the allocation of resources, including management interventions and access to health care.

Better methods to identify the incident diarrheal disease in the community would improve the burden of disease estimates and provide tools for tracking the impact of public health interventions; if the methods allowed for real-time detection of cases, they could also improve outbreak detection and response. Household surveys are considered to be the best way to measure the incident diarrhea in communities, and evidence suggests that the optimal recall period for these surveys is 48 hours.⁵ To measure changes in incident diarrhea, however, these surveys must be conducted for long periods, which are resource intensive and likely to lead to research fatigue, increasing dropout rates, compliance errors, and demographic challenges.^{6,7}

As mobile phones become increasingly used globally, they present an opportunity to communicate with households

about disease events.⁸ Using phones to report diarrheal disease events could provide many advantages over other surveillance methods, including reduced study fatigue compared with in-home visits, real-time reporting that could facilitate laboratory confirmation of etiology, and reporting of mild and moderate symptoms. However, the feasibility and acceptability of this surveillance method for diarrheal illness is unknown.

As diarrhea is one of the major causes of death in Bangladesh, this high-risk area is a suitable place to investigate new surveillance methods for diarrheal disease.⁹ In 2014, an estimated 88% of the population in Bangladesh owned a mobile phone and the average tariff of a prepaid mobile phone in Bangladesh was one of the lowest in the world,^{10,11} which suggested that people living in communities at risk for diarrheal outbreaks to some degree might be able to use this technology for disease reporting. This study aimed to pilot a mobile phone-based surveillance system “the cholera phone” for diarrheal disease in urban Bangladesh and to compare its performance with that of traditional household surveys.

METHODS

Study site and population. The study was conducted in East Arichpur, an urban, low-income community located in the Tongi subdistrict of Dhaka, Bangladesh.¹² The study was nested within a longitudinal study of diarrhea incidence and water use among households selected to represent various levels of water scarcity experiences.

Households were enrolled in the longitudinal study on a rolling basis from June 3, 2014 to June 1, 2015. Study staff visited households identified as being eligible for the study and approached the household head and other members for consent to participate. Households were excluded from the broader study if they were planning to move outside of East Arichpur within 6 months from enrollment or if 50% or more of household members refused to participate. If households migrated out of the study area, another household was

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randomly selected to replace it. As part of the longitudinal study, we collected data on the sociodemographics of the enrolled households and age and gender of household members. Households were asked to consent to enroll in the study, to report diarrheal episodes of family members, and to receive home visits once every 6 weeks to complete additional surveys about diarrheal illness.

Focus group discussions (FGDs). Anthropologists conducted eight FGDs to understand participants' perceptions of diarrhea, general attitudes about mobile phones, and the perceived advantages and disadvantages of participating in the study, with the goal of improving the mobile phone surveillance system. Two occurred in August 2014 and six more were conducted in December 2014. Caretakers were primarily targeted because they were responsible for using the mobile phones and discussions were held at places convenient for respondents, such as local schools. In August 2014, we conducted two FGDs which consisted of one group of 11 females and one of eight males aged 18–65 years. In December 2014, we included six more groups with four to six participants. Three focus groups with a total of 15 males and three with a total of 21 females aged 18 to 48 years participated. The participants were selected from different neighborhoods in East Arichpur to represent geographical diversity. The discussions were recorded using a tape recorder and study staff took notes on nonverbal communication and body language. The recorded discussions were transcribed in Bengali, and notes on nonverbal communication were inserted in the text. Transcripts were analyzed based on emerging themes, and preliminary concepts from the FGD guidelines (deductive coding) were conducted based on these categories.¹³

Diarrhea surveillance and incidence comparisons. For each enrolled household, a primary caretaker was identified, either a male or female household member who was primarily responsible for taking care of household chores and who was home most often. The caretaker received a non-smart model mobile phone (Maximus m8i; Dhaka, Bangladesh, approximate cost of US\$12), with basic functions for calling and sending text messages. Caretakers were given a demonstration on how to use the phone and were asked to call study staff when someone in the household experienced diarrhea, which we defined as three or more loose stools in 24 hours¹; the study phone number was preprogrammed into the phone. Caretakers were also provided with a laminated poster with instructions on how and when to call to report diarrhea (Figure 1). From August 2014, every fortnight households received an automated call reminding them to report diarrheal episodes. Preliminary qualitative findings from August 2014 (see methods and results) made us eliminate the word “diarrhea” to “three or more stools in 24 hours” in all communication material for the participants and data collection tools on the August 12, 2014, and we therefore excluded the data collected before this date from the analysis. Moreover, because of civil and political unrest in Dhaka, the study was suspended between January 6 and February 1, 2015.

The phone had a preinstalled SIM card, where the last three digits of the telephone number corresponded to a unique three-digit household identity number. This number was also visible externally on a laminated identity tag attached to the phone so that the telephones could be easily identified and associated with the reporting household. The phones were credited with 100 taka (approximately US\$1.30) at the start of the study and

once every 6 weeks to enable participants to call the call center without incurring costs for the calls. However, households could use any remaining phone credit for personal calls.

When caretakers called to report diarrheal episodes, there were two study staff trained to answer the calls. They received calls between 07:00 and 22:00 every day; caretakers who called after hours had their calls returned as soon as the staff were back on duty. Study staff confirmed the household identification number and asked the caller questions from a structured questionnaire to confirm that the diarrheal episode met the case definition of diarrhea. Then, they set up an appointment with the caretaker for an in-house visit the following day to collect additional data about the diarrheal episode (treatment, food eaten, water source and water quantity used, etc) and request a rectal swab from the patient for laboratory testing (laboratory testing results and additional episode data are to be reported elsewhere). If the person with diarrhea was not available for a home visit within 48 hours of this first phone

FIGURE 1. Instruction sheet on reporting diarrhea. The Bengali-translated instruction poster on reporting diarrhea to the call center for study participants of East Arichpur, Dhaka, from June 2014 to June 2015. Translation from top: “(on red background) If three or more loose stools in 1 day... (On orange background) Call us using the icddr, b number below or press on the five button on your mobile phone for a little while. (Points on banner) We will want to know the ID-number tagged to your mobile phone and the ID number of the ill household member. We will discuss when the ill person will be available (within 48 hours) in the household so we can collect a rectal swab from him/her. When we have analyzed the sample, we will call you and let you know if you have cholera or not. (On white background) We are open from 7 PM to 10 PM. If you call after 10 o'clock at night, we will call you back in the morning the day after. (In red writing) If you observe that, after calling us, the condition of the ill person becomes more severe (bloody stools, enormous amounts of stools or colorless stools) then do not wait for us to visit you, but seek medical care with a doctor.” This figure appears in color at www.ajtmh.org.

call, no follow-up in-house visit was conducted for that episode (Figure 2).

From September 2014 to June 2015, the data collection team visited all enrolled households once every 6 weeks to collect data on diarrhea experienced by any household members within the previous 48 hours. Any participants still experiencing symptoms at the time of the visit were asked to provide a rectal swab for testing.

The annual diarrhea incidence rate (IR) was calculated for the cases reported via mobile phone and for the diarrhea cases reported with a 48-hour recall period during the in-home survey from August 12, 2014, to the study end date. Person-time at risk was calculated as the person-time when the household had a study phone for the mobile phone surveillance, and for the in-home surveys was calculated as the cumulative total of the 48-hour recall periods for all of the home visits. The incidence rate ratio (IRR) between the two methods was estimated, as well as the 95% confidence intervals.

Ethics. Study staff collected informed written consent from all study participants and guardians of participating children. This study was approved by the ethical review committee of icddr,b in Bangladesh (protocol number PR-14006).

RESULTS

Reporting from FGDs. During the first rounds of FGDs conducted in August 2014, the participants used the English word “diarrhea” and described it as an interchangeable term with “cholera.” They defined these terms as a severe bout of loose stools where treatment with oral rehydration solution was ineffective and where hospitalization was often needed.

“First it’s loose stools (*patla paykhana*), when more severe it’s called diarrhea (*diarrhea*). . .”

The FGD participants used the word *patla paykhana* (loose stools) to describe a syndrome that most closely corresponds to the WHO definition of diarrhea; the words *pet kharap* (bad

stomach) and *pet naram* (soft stomach) were also sometimes used. Based on the findings, we changed the word “diarrhea” to the Bengali term “*patla paykhana*” (loose stools) in all research material from August 12, 2014. Some participants mentioned that they would have reported the loose stools if it had been more severe, such as five to six loose stools in 24 hours. Many respondents reported that eating food from outside the household could cause loose stools or diarrhea and some reported that they believed physical stress caused this illness. Some also reported that they experienced diarrhea for unknown reasons.

During the first round of FGDs in August 2014, participants reported benefits of using the phone, such as having the extra call credit on phone. This was particularly attractive for female participants because it enabled them to call geographically distant relatives.

Participants indicated several barriers to reporting diarrhea using the mobile phone, including feeling discouraged about calling the switchboard as the welcome message at the central switchboard was in English and a fear of consequences if the phone was stolen or misplaced. A small number of participants reported technical issues such as low network coverage, low battery capacity, and poor sound quality of the mobile phone. A summary of major themes from the FGD sessions is provided in Table 1.

During the second round of FGDs conducted in December 2014, a male participant said he did not want to report loose stools because of the hassle and time commitment of someone coming to his house to collect a sample. Participants reported that they did not call when they had loose stools because they considered bowel movements a private matter and were ashamed of discussing them. In addition, they feared being admitted to hospital if they reported diarrhea. Participants also mentioned that they had no incentives, such as receiving treatment, to call and report diarrhea episodes.

“They only give us money and not the medicine, so what is the benefit of calling? We are not getting any consultation or treatment.”

FIGURE 2. Diarrhea surveillance using mobile phones. From the selected households, diarrhea was reported to the call center via the mobile phone. The research team visited the household and collected a rectal swab. This figure appears in color at www.ajtmh.org.

TABLE 1

Summary of themes, sample questions, and outcome of the eight focus group discussions conducted in the study area in August and December 2014

Category	Sample question	Summary of results
Perception of diarrhea, loose stools, and cholera	What do you understand about the word “diarrhea”?	Passing loose stools from two to six times a day, with a frequency of every half an hour to every hour A waterborne disease Associated with cholera A condition much more severe than loose stools Incidence of loose stool, which is not treatable with ORS, and therefore, leads to hospitalization Vomiting primarily, second—fever, pain in stomach, weak body, gas, bad odor of stool, decreased appetite, sounds from stomach, and weak sensation in body after defecation is described Less severe than diarrhea, a more normal condition Passing loose stools two to three times per day Treatable with ORS Terms used to describe loose stools in Bengali were as follows: <i>Patla paykana (loose stools)</i> <i>Pet kharap (bad stomach)</i> <i>Pet naram (soft stomach)</i>
	What are the signs and symptoms of diarrhea?	Symptoms: loose stools are without other symptoms, pain in stomach, bloating of stomach, gas, decreased ability for digestion, and discomfort during defecation
	What are loose stools?	Street food intake/rich food intake Physical stress, unknown reasons
General attitude toward mobile phones	What is the reason for having diarrhea or loose stools?	Relation to mobile phones ever since it came on the market in 1997. Now there is no house without a mobile phone
	What do you think about mobile phones in general?	Talking to friends and family Getting updated on bad and good news, listening to music, watching videos, and recording things
	What is the main purpose of a mobile phone?	Calling friends and family and getting good and bad news
Advantages and disadvantages in the diarrhea surveillance system	Have you been using the provided mobile phone? For what purposes?	Calling and solving problems at home for the male participants. Risk reduction in relation to diarrheal disease; benefit of having the extra credit on phone
	What do you see as an advantage to providing mobile phone?	Female participants being able to call their fathers' house
	What do you think is an obstacle to using the provided mobile phone?	Expressed concern for the mobile phone getting stolen. SIM card with them in another phone. Technical barriers and language barriers
Reasons for not reporting loose stools	What could be the reason for not reporting loose stools to the call center?	Because of the hassle and time commitment of someone coming to collect a sample Bowel movements are a private matter and participants were ashamed of discussing it Fear of being admitted to hospital if they reported diarrhea Lacking incentives, such as receiving treatment, and to call and report diarrhea episodes Self-treatment after experiencing one or two episodes of loose stools

ORS = oral rehydration solution.

Participants reported self-treatment with medicines such as Flagyl (metronidazole) after experiencing one or two episodes of loose stools. They said that frequently, after self-treatment, they did not experience more loose stools and therefore did not call. Participants reported misunderstandings about the study's sample collection process. For example, some thought they had to collect their own stool in a pot before the visit of the research team member. Others thought that loose stools or diarrhea during nighttime should not be reported and did understand that the “the missed call” during nighttime would make the study team contact them the next day to collect a rectal swab. One participant said,

“If I report at night nobody will come to take sample, so it is better to call in the morning. In the morning, since there was no more loose stool, I decided not to call (the call center).”

Results from diarrhea surveillance. A total of 419 households were enrolled in the study and provided with a mobile phone. Fifty-seven households moved to a different location within the site during the study period, leading to a total of 476 households for which baseline surveillance data were collected (Figure 3). The household structure of the

FIGURE 3. Risk time for diarrhea for households with a mobile phone (gray bar) in East Arichpur, Dhaka. Dropout rate and households that moved within study area are marked in color. This figure appears in color at www.ajtmh.org.

participating household mostly consisted of more than four members (91%), of which 59% had a daily income of US\$2 or less. Most households already owned a mobile phone before participating in the study (Table 2). The mobile phone surveillance included 739.6 person-years of observation and the in-home surveillance included 33.0 person-years of observation (Table 3).

A total of 117 calls from 87 different households reported diarrhea between August 12, 2014, and June 2015. One hundred five cases were available within 48 hours and received a home visit and provided a rectal swab (Figure 4); the remaining 12 cases were not available for a home visit within 48 hours. Sixty-nine (79%) of the diarrhea case households did only call once. The diarrhea IR was 0.16 (95% CI:

0.13–0.19) per person-year for the mobile phone surveillance and 0.33 (95% CI: 0.18–0.60) per person-year by the routine in-home survey. The IRR was therefore 2.11 (95% CI: 1.08–3.78) (Table 3). None of the diarrhea events reported during in-home surveys were reported through the mobile phone surveillance. The diarrhea IR for children aged between 2 and 5 years was 0.21 (95% CI: 0.12–0.38) based on 12 reported cases with mobile phone. No cases were identified with the in-home survey.

DISCUSSION

The estimated incidence of diarrhea using in-home surveys was higher than that from mobile phone reporting (IRR of 2.35 (95% CI: 1.26–4.37)) and none of the episodes reported during the home visits had been reported by phone. Although the difference in IR between the two methods differed significantly, the in-home survey method also had a wider confidence interval because of less person-time at risk. There were a number of limitations to using mobile phones to report diarrheal episodes, including possible misinterpretation of what constituted a disease episode for study participants, disincentives to report diarrhea because of the inconvenience of a home visit and request for a rectal swab, and social discomfort with discussing bowel movements with a stranger by phone. The lower incidence estimated through mobile phone surveillance compared with household visits is likely due to these disincentives to report diarrhea by phone. Nonetheless, despite these barriers to using the phone reporting system, 18% of the participating households did report at least one diarrheal episode by phone during the study period. Because episodes were reported in real time by phone, they allowed for the collection of rectal swabs for laboratory testing. Even if this

TABLE 2
Baseline household characteristics

Socioeconomic and demographic characteristics	Households, N = 476
Household structure	
Nuclear family with or without extended family (4+ members)	433 (91%)
Unrelated members	8 (2%)
Single member	35 (7%)
Daily income per person in USD	
< 1 USD	72 (15%)
1–2 USD	210 (44%)
2–3 USD	114 (24%)
3–4 USD	67 (14%)
> 4 USD	13 (3%)
Number of mobile phones per household before study enrollment	
0	24 (5%)
1	199 (42%)
2 or more	253 (53%)

Household structure, monthly income quintile, and mobile phone ownership in the study households enrolled in East Arichpur, during June 2014 to June 2015.

TABLE 3

Diarrhea cases reported, person-time observed, and diarrhea IR among study participants in 476 enrolled households in East Arichpur, during August 12, 2014 to June 2015

	Mobile phone surveillance	In-home survey
Number of diarrhea cases	117	11
Total person-years at risk	739.6	33.0
Average person-years of observation contributed by each household member	0.44	0.02
IR per person-year (95% confidence interval)	0.16 (0.13–0.19)	0.33 (0.18–0.60)

IR = incidence rate.

surveillance is suboptimal compared with household surveys for estimating incidence, it might be useful for research where real-time reporting of episodes is more important than complete capture.

Findings from our FGDs provide some clues about how use of the mobile phone reporting could be increased. Participants noted discontent owing to the lack of treatment for diarrhea provided by the study, and future efforts to include home-based oral rehydration therapy or physician advice could improve the use of the call center. However, few data exist, showing that these kinds of incentives actually improve reporting. To date, only few studies exist on the effect of using compensation for clinical trials and fewer yet on field trials for reporting diarrhea.¹⁴

The incidence of diarrhea was lower than expected in this study, from both the mobile phone reporting and the in-house surveys for an area such as East Arichpur, with poor sanitation and hygiene infrastructure.¹² To the best of our knowledge, there are presently no estimates of diarrhea IRs for all age

groups in Bangladesh or East Arichpur. However, a study in 2003 on diarrhea in 2- to 5-year-old children in a slum area of Mirpur in Dhaka reported a diarrhea IR of 1.8 per child-year.¹⁵ Our data reported a considerably lower IR of 0.21 (95% CI: 0.12–0.38) for the same age group. One major limitation of our estimates is that our data collection period did not cover a complete year, and diarrhea incidence is seasonal in Bangladesh, with peaks often occurring in the summer months when our surveillance was not active. This could have contributed to lower incidence measured here, as could real reductions over time in diarrheal disease risk.

Our study underscores the importance of using social science methods to optimize surveillance strategies and improve communication with study participants. Our methods allowed us to identify differences in understanding the meaning of the word “diarrhea” and to change our communication with participants to better identify illnesses consistent with our case definition. In addition, participants in the FGDs were able to offer insights into why many families may not have reported diarrhea episodes by phone and some possible ways to increase participation during future efforts.

Households were comfortable with mobile phone technology, but participation was likely limited by incentives to report. Future initiatives to use mobile phone-based reporting will improve their chances of success if they work with communities to understand and respond to these incentives. Although our study showed that mobile phone-based surveillance strategies for reporting diarrhea may underestimate true incidence of disease, these methods could be used in studies where real-time reports of disease outbreaks and sample collection are a priority over complete disease episode counts, or as an adjunct to other surveillance strategies.

FIGURE 4. Cases of diarrhea reported through the mobile phone surveillance system. The dotted line indicates August 12, and the dashed lines indicate the break in the study due to unrest. This figure appears in color at www.ajtmh.org.

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