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Feasibility and acceptability of mobile phone data collection for longitudinal follow-up among patients treated for obstetric fistula in Uganda

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ABSTRACT

Rapid dissemination of mobile technology provides substantial opportunity for overcoming challenges reaching rural and marginalized populations. We assessed feasibility and acceptability of longitudinal mobile data capture among women undergoing fistula surgery in Uganda ($n = 60$) in 2014–2015. Participants were followed for 12 months following surgery, with data captured quarterly, followed by interviews at 12 months. Participant retention was high (97%). Most respondents reported no difficulty with mobile data capture (range 93%–100%), and preferred mobile interview (88%–100%). Mobile data capture saved 1000 person-hours of transit and organizational time. Phone-based mobile data collection provided social support. Our results support this method for longitudinal studies among geographically and socially marginalized populations.

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Collecting longitudinal health outcome data from marginalized individuals are particularly challenging in communities where there is limited access to care and poor infrastructure. The broad dissemination of mobile technology offers one solution for overcoming certain challenges to longitudinal data collection among dispersed, marginalized, and rural populations of patients. Mobile technology is widespread across sub-Saharan Africa, including in Uganda. In 2015, the Uganda Communications Commission (2015) reported 22.6 million mobile cellular subscriptions, equal to 56.3 per

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100 inhabitants, and representing a 60% increase in cellular subscriptions since 2010 (Uganda Communications Commission, 2010). Given the rapid uptake of cellular use, mobile phone penetration continues to increase (Grameen Foundation, 2008). Mobile technology has been shown to be a successful platform for populations across many sectors and activities, including social connection, education, banking, income generation, activism, and health care (Hellstrom, 2010). The use of mobile technology could permit low-cost long-term follow-up among research participants belonging to geographically and socially marginalized populations, yet the feasibility and acceptability of this methodology among women affected by obstetric fistula has not been assessed.

Obstetric fistula, a debilitating maternal birth trauma mainly due to prolonged obstructed labor, is an important maternal morbidity largely affecting women in sub-Saharan Africa and Asia. Prevalence and incidence data are poor, yet estimates suggest that two million women globally may be living with obstetric fistula, with annual incident cases ranging as high as 100,000 (Wall, 2006; WHO, 2006). Women living with obstetric fistula experience severe physical, psychological, and social sequelae (Ahmed & Holtz, 2007; Browning & Menber, 2008; Roush, 2009; Siddle et al., 2013; Turan et al., 2007) and are a paradigm of a marginalized population. Delays in treatment are common due to costs of surgery, sparse transport, and lodging; and poor geographic access to medical services (Bellows et al., 2014; Kabayambi et al., 2014; Phillips et al., 2016; UNFPA and Ministry of Health, Uganda, 2003; UNFPA & Family Care International, 2007; Woldeamanuel, 2012). Obstetric fistula occurs most frequently in remote geographies (Direct Relief, 2016), largely correlating to availability of emergency obstetric care; thus, affected women are often geographically dispersed. Furthermore, risk of fistula follows a social gradient consistent with socioeconomic patterns of health care inequity (Maheu-Giroux et al., 2015, 2016), further complicating patient access to care and follow-up due to marginalization of this population. Treatment facilities, on the contrary, are typically highly specialized referral centers located in major cities, which can be difficult to access for the surgery itself, placing a further significant travel burden on study participants for in-person longitudinal research participation.

Longitudinal research is of significant interest among women and girls affected by obstetric fistula due to nascent research suggesting persistence of fistula-related morbidities (Anzaku et al., 2016; Bangser, 2007; Browning, 2006; Donnelly et al., 2015; Khisa & Nyamongo, 2012; Landry et al., 2013; Pope et al., 2011; Turan et al., 2007; Women's Dignity Project & EngenderHealth, 2007), fistula recurrence, and adverse subsequent reproductive outcomes (Delamou et al., 2017). Most clinical follow-up is short

term, within the three months following surgery. The sequelae, on the other hand, may persist following fistula repair, either failing to resolve or not occurring until after short-term follow-up is complete. This lack of follow-up may result from the same underlying geographic dispersion and lack of access that resulted in the woman developing the fistula, significantly reducing quality of life for the affected women and limiting the quality of the evidence base regarding outcomes. The researchers' aim in conducting this study was to assess the feasibility and acceptability of longitudinal mobile phone data capture of outcomes among women affected by obstetric fistula in Uganda accessing care at Mulago National Referral and Teaching Hospital in Kampala within a longitudinal study of women's recovery experiences following surgical repair of fistula (Byamugisha et al., 2015).

Methods

The researchers used an exploratory sequential mixed methods design, a quantitative longitudinal cohort followed by a nested qualitative component, in order to explore nuances in participant experiences in the year following genital fistula repair. The target population was women accessing obstetric fistula surgery at Mulago National Referral and Teaching Hospital in Kampala, Uganda. Fistula repair is provided by the urogynecology division as both an ongoing surgical service and supplemented by four to five annual fistula repair camps.

Quantitative component

A longitudinal cohort of 60 women was recruited for study participation from December 2014 to June 2015. Women were eligible for participation in the longitudinal cohort upon completion of initial examination and clearance for fistula surgery at Mulago Hospital, if they spoke Luganda or English, resided in a community with cellular telephone coverage, and were able to provide informed consent for study participation. Patients confirmed for surgery were approached and screened for eligibility by the research staff, who obtained written informed consent in their preferred language from interested patients. Where eligible participants were unable to be approached prior to surgery, they were asked to participate post-operatively, following sufficient recovery (within 2–3 days following surgery) to be able to converse with research staff. Data were captured from longitudinal study participants at baseline, and 3, 6, 9, and 12-month post-surgery. The baseline questionnaire was administered in person by the local research coordinator at study enrollment and included basic socio-

demographic questions, obstetric history, and measures of physical and psychosocial status (Byamugisha et al., 2015). No subsequent in-person data collection occurred; however, respondents who expressed significant health concerns were encouraged to follow up with a local provider. All four post-discharge follow-up surveys were administered over mobile telephone by the research staff. Follow-up surveys included the assessment of socio-demographic characteristics that may have changed since baseline, physical and psychosocial status, and respondents' experiences and satisfaction with the mobile data collection method. Specific to the mobile data collection method, participants were asked how difficult it was for them to answer these questions over the phone (response options were made on a five-category Likert-type scale ranging from not at all to extremely), whether they would have preferred to respond to these questions in person instead of over the phone (response options: yes, no, not sure), and for their general comments on the mobile data collection method.

Participants were provided with cell phones and monthly airtime contracts for the duration of the follow-up (participants were allowed to keep their phones after study follow-up was completed). Data were also captured on distance to participant's residence, cost to reach the participant's residence from Mulago Hospital on public transit, and the time in minutes that it generally took to reach the participant's residence, on both public and private transits. Petrol costs associated with private transport were calculated using average fuel economy rates for light duty petrol—using vehicles established by a recent Ugandan study (Mutenyo et al., 2015), combined with average petrol per liter costs during the study period. Cost estimates were rounded to the nearest \$0.10 United States Dollars (USD) and 100 Ugandan Shillings (UgX). Contact tracking data were maintained for each participant for each data collection period, including the number of calls made to reach the participant at the primary number (the participant's number) and any secondary numbers (numbers belonging to family or friends). Any special efforts required to reach the participant or challenges experienced were noted on a structured form.

Qualitative component

A selection of longitudinal cohort participants was invited to participate in an in-depth interview following the conclusion of the 12-month longitudinal study to qualitatively explore women's experiences of reintegration and physical and psychosocial recovery following fistula surgery, including experiences, challenges, and supports. The researchers did not explicitly seek to understand the acceptability of the mobile phone data collection method when developing the interview guide and question prompts. Thirty

of the 40 women invited to participate in the in-depth interview completed an interview, at which point data on women's experiences of reintegration were thematically saturated. Interviews lasted approximately 1 to 1.5 h each and were conducted by the local research coordinator who the participants were familiar with given their participation in the longitudinal cohort.

Analysis

Univariate analyses were performed to describe the socio-demographic characteristics of participants at baseline and the estimation of travel time and costs. Medians, interquartile ranges, and ranges were calculated for continuous variables after assessing normality of distribution, and proportions for categorical variables were analyzed. To understand the potential impact of socioeconomic status and distance on feasibility and accessibility outcomes, these were further assessed by prior household mobile phone ownership and distance between residence and hospital (below the median of 57 km, or above) using Fisher's exact test. All analyses were performed using Stata v14 software (StataCorp, College Station, TX). Transcripts from in-depth interviews were coded using inductive and deductive codes within ATLAS.ti software using a series of inductive and deductive codes developed from the interview guide and arising from the data itself. Data were analyzed to understand women's experiences recovering from fistula surgery, including sources and types of social support. Data were coded and analyzed by the Ugandan research coordinator (HN) and an experienced American qualitative researcher (AE), with discrepancies resolved via discussion. A number of themes emerged relevant to women's post-surgical reintegration experiences; this article's focus is limited to the theme of social support as it related to women's participation in the longitudinal cohort study. Relevant themes that arose in the data included sources and types of social support and impact of social support on recovery.

Ethics approval

The study protocol was approved by the Makerere University School of Medicine Research and Ethics Committee (Ref# 2014-052), the Uganda National Council on Science and Technology (ADM 154/212/01), and the University of California, San Francisco Human Research Protection Program, Committee on Human Research (IRB# 12-09573 and IRB# 15-17467). All individuals eligible for the research underwent an informed consent process, and participants provided written or thumbprint confirmation of consent.

Table 1. Socio-demographic characteristics of study participants at study enrollment, overall and for nested qualitative cohort.

	Longitudinal cohort <i>n</i> = 60		Nested qualitative cohort <i>n</i> = 30	
	<i>n</i>	%	<i>n</i>	%
Age ^a	28 (21–36)		31.5 (27–38)	
Marital status				
Married	7	11.7	4	13.3
Living together	22	36.7	11	36.7
Divorced/separated	16	26.7	11	36.7
Widowed	3	5.0	0	–
Single/never married	12	20.0	4	13.3
Participant lives with				
Alone	2	3.3	3	6.7
Husband	24	40.0	11	36.7
Young children only	11	18.3	6	20.0
Adult children only	4	6.7	3	10.0
Parents	8	13.3	2	6.7
Others	11	18.4	5	16.6
Educational attainment				
None	10	16.7	5	16.7
Some primary	24	40.0	10	33.3
Completed primary	17	28.3	9	30.0
Some secondary or more	9	15.0	6	20.0
Work outside of home	26	43.3	12	40.0
Primary source of financial support				
Self	17	28.3	10	33.3
Husband/partner	24	40.0	13	43.3
Relatives	19	31.7	7	23.3
Household assets				
Piped water	9	15.0	6	20.0
Radio	35	58.3	19	63.3
Bicycle	10	16.7	3	10.0
Flush toilet	4	6.7	3	10.0
TV	17	28.3	8	26.7
Electricity	26	43.3	39	65.0
Mobile phone	39	65.0	17	56.7
Land	28	46.7	11	36.7

^aMedian (IQR).

Results

Participants

Socio-demographics characteristics of the longitudinal cohort participants at study enrollment are presented in Table 1. Median age was 28 y (IQR: 21–36 y). The greatest proportion of participants lived with their husbands (40%), with the remaining 60% reporting a range of other arrangements, including alone, with young or adult children, with parents, or others. The vast majority of participants resided in the Central region of Uganda, with three in the Eastern region. Just under half of participants had completed primary education or higher (43%). Less than half of participants worked outside of the home (43%), and less than one-third reported financial self-sufficiency (28%). Common household assets included radio (58%), electricity (43%), and mobile telephone (in household but not belonging to participant: 65%); 47% of households owned land.

Table 2. Characteristics of mobile data collection for 12-month follow-up among post-fistula surgery longitudinal cohort participants, number of calls and challenges experienced, across data collection period.

	3 Months	6 Months	9 Months	12 Months
Calls to primary number				
Median (IQR)	1 (1–2)	1 (1–3)	1 (1–4)	1 (1–2)
Range	1–9	1–14	0–11	1–10
Calls to secondary number				
Median (IQR)	0 (0–1)	0 (0–1)	0 (0–2)	0 (0–0)
Range	1–14	0–24	0–22	0–23
Any challenges	7 (11.7)	5 (8.3)	4 (6.7)	4 (6.7)
Poor network	5 (71.4)	2 (50.0)	1 (25.0)	1 (33.3)
Help needed to track	1 (14.3)	1 (25.0)	3 (75.0)	1 (33.3)
Physically tracked	1 (14.3)	1 (25.0)	–	1 (33.3)

Feasibility

Participant retention across the mobile data collection points following surgery was high: 98% at 3 months, 95% at 6 months, 92% at 9 months, and 97% at 12 months (not shown). The majority of data collection was conducted over the phone (98% at 3 months, 93% at 6 months, 100% at 9 months, and 95% at 12 months); however, a few participants attending follow-up appointments at the urogynecology clinic were captured in person, and it became necessary to track one participant to her home. Most individuals reported having no difficulty with answering the questions over the phone (92% at 3 months, 100% at 6 and 9 months, and 95% at 12 months). Three distinct participants at three months and 12-month post-surgery indicated that they felt it was “a little” difficult, and one participant at three months reported it to be “very” difficult. No differences were identified in difficulty of response by prior household mobile phone ownership or by distance from hospital (not shown).

Across all mobile data collection points within the 12-month study follow-up, the median number of calls to the primary number (participant’s own mobile, provided by the researchers) was 1; however, IQRs and full range varied across the four periods (Table 2). Median number of calls to any secondary numbers provided by the participant, including the numbers of family or friends, was zero across the four data collection periods, but also ranged widely. Challenges in capturing data from participants were reported in 12% of three-month surveys, 7% of six- and nine-month surveys, and 5% of twelve-month surveys. The most common challenge encountered was poor cellular network.

Acceptability

Nearly, all participants said they would not have preferred to participate via in-person survey (88%, 98%, 100%, and 98%, at 3, 6, 9, and 12-month post-surgery, respectively). No differences were identified in participation

Table 3. Geographical dispersion of post-fistula surgery longitudinal cohort participants.

	Median (IQR)	Range
Distance to residence (km)	57 (11.5–131)	2–285
Minutes to travel to residence (public)	112.5 (50–165)	10–380
Cost to travel to residence (public)	7,000 (300–15,000) UgX \$2.10 (1.00–\$4.60) USD	1,000–35,000 UgX \$0.30–10.60 USD
Minutes to travel to residence (private)	81 (30.5–129)	5–324
Cost to travel to residence (private)	23,600 (4,800–54,200) UgX \$6.70 (\$1.40–\$15.50) USD	800–117,900 UgX \$0.30–\$33.70 USD

Note: USD values are rounded to the nearest \$0.10, while UgX are rounded to the nearest 100.

method by prior household mobile phone ownership or by distance from hospital (not shown). When asked for comments on the mobile data collection, most participants reported feeling happy that they did not have to leave their homes and were able to answer the survey in a private location at their residence at a time of their convenience. However, some participants shared their opinions about feeling less free with data capture on the phone, saying for example, “*You cannot say so much on the phone,*” and missing the close interaction the in-person interview enabled, “*I want to see the interviewer (face-to-face).*” Two respondents reasoned that visible signs and symptoms of any medical problem that they could be having would have been identified in an in-person interview but missed on phone interviews.

Cost

Characterizations of the distance between study participants’ homes and Mulago Hospital are presented in Table 3. Median distance from Mulago Hospital to participant residence was 57 km (IQR 11.5–131), with the closest and furthest participants residing 2 and 285 km away, respectively. Median travel time on public transit was 113 min (IQR 50–165), with minimum and maximum time 10 and 380 min. Were the trip to be made in a private vehicle, median travel time would be reduced to 81 min (IQR 31–120), with a range of 5–324 min. Cost values in Table 3 include both Ugandan Shillings and US dollars. One-way public transit cost a median of \$2.10 USD (IQR \$1.00–\$4.60), with a range from \$0.30 to \$10.60 in 2015 mid-year exchange rates (PoundSterling Live, 2017). Median one-way transit cost via private car would have been \$6.70 (IQR \$1.40–\$15.50), with range \$0.30–\$33.70.

Initial project investments specific to mobile data collection included mobile phones (\$15 each) and SIM cards (\$1 each) for each participant. During the course of the study, two participants needed replacement phones. The total cost for phones and SIM cards was \$992. Continuing project investments specific to mobile data collection included monthly participant airtime (\$4 per person per months), and airtime for study

coordinator to follow up with participants (\$25 per month), for a total of \$3180 across the 12-month study.

Overall, by conducting the study data capture over the phone, a total of 987 h of person time in round-trip public transit or 760 h in round-trip private transit were saved, a savings potentially attributable to both the study coordinator and study participants. The cost savings of avoiding travel on public transit was \$1391 USD and on private transport \$4353 USD, not including the value of person time which is likely to have been substantial.

Qualitative insights on social support via mobile data collection

While participants' perspectives on feasibility and acceptability of mobile data capture in the nested qualitative study conducted at 12-month post-surgery were not explicitly included within the interview guide, a series of comments arose around the unintended consequences of the mobile phone data collection method in response to questions regarding sources and types of social support. In sharing their experiences and sources of social support during the recovery period, about one-third of participants brought up the emotional support that they had received from consistent contact with the research coordinator who collected both the quantitative from the longitudinal cohort study and the qualitative data from the nested study. From their comments, it was clear that participants did not perceive the research personnel to be distinct from the clinical personnel. Some participants described appreciating the consistent follow-up they received through the data collection calls as they felt that someone was caring for them and checking on them:

Health workers are our role models. You love us more than any other relatives. You know what it means to be alive and what it means to give birth, and [you] are the only people that value our lives. You know how to comfort us as we get back to life I feel that the health workers are putting in a lot of efforts to [make sure] that I get well. (Interviewee, age 41)

Others appreciated the opportunity to ask questions of the research coordinator, who is not a clinician, but who encouraged women to return for follow-up at the urogynecology clinic when they expressed significant physical concerns. Several individuals perceived that their interactions with the research coordinator provided some important counseling. Finally, several women expressed gratitude for the phone and airtime they received in order to participate in the study. These experiences are expressed in the participant narratives below:

Counseling is what has mostly been helpful [to enable me to heal]. You (interviewer), those people that I have at home, as well as my children [have been counseling me] That is what has mostly enabled me to get healed. (Interviewee, age 42)

There wasn't any [organization] which helped me aside from the hospital. [After returning home], I used to get airtime and calls from my health worker to share encouragement and advice. Whenever I had pain, she would tell me what to do. (Interviewee, age 35)

Discussion

In this study of a marginalized and geographically dispersed patient population in Uganda, longitudinal data collection via mobile phone was feasible, acceptable, and provided cost saving benefits while minimizing participant response burden. Additionally, the communication opportunity provided during the course of mobile data capture was positively received as social support by a number of participants. These findings support the use of mobile data capture for subsequent longitudinal studies among other marginalized populations sharing characteristics of this particular patient population of women affected by obstetric fistula.

In today's context of increasing mobile technology access, the evaluation of mobile data collection techniques has largely been focused on understanding the benefits and disadvantages of automated methods such as audio computer-assisted self-interviewing (ACASI), interactive voice response (IVR) telephone interviewing, and text message (SMS)-based systems, largely to understand achievability of more valid results of sensitive attitudes and behaviors including alcohol-related problems, physical and sexual abuse, and sexual orientation (Midanik & Greenfield, 2008). Significantly less focus has been paid in recent years to the simpler data collection technology of voice-to-voice, despite unique benefits to this method which include increased access to broad geographies, hard to reach populations, and closed sites (Deakin & Wakefield, 2014). Indeed, the utility of this data collection method was not obsolete within this particular patient population, and the relationship building within voice-to-voice communication was important for maintaining high study retention (Mitchell et al., 2015).

Furthermore, provision of mobile phones to study participants by study staff may also be an important facilitator of study participation and retention among vulnerable populations (Stewart et al., 2018). Indeed, 65% of longitudinal study participants reported a mobile phone in the household, but none reported that they were the primary owner of the phone. These findings appear to be consistent with other research describing significant gender disparities in access to technology despite increasing access to mobile telephones in rural Uganda and elsewhere (Burrell, 2010; GSM Association, 2018). Our findings on feasibility, accessibility, and retention suggest that women's differential access to mobile technology did not adversely impact study participation and data collection, although future

research in other areas or using different technology may need to consider the gender implications of differential access to mobile technology.

The selection of any mobile data collection technique should prioritize the particular needs of the study, balancing the advantages and disadvantages to the data collected (Kahn et al., 2010). The findings from this study highlight the vital importance of the social support component provided by the voice-to-voice component on this approach for this socially isolated and stigmatized population. Indeed, important limitations exist to telephone-based interviewing (Gliksman et al., 1987), including the inability to collect any data beyond self-report; however, as technologies advance, it may be feasible to implement various combinations in order to achieve a combination of reporting. Biologic and symptomatic data collection may be possible through the provision of phone-compatible specimen collection tools. Furthermore, any potential impact of the interviewer on the interviewee that may bias the study results must be carefully considered.

In our longitudinal data collection using voice-to-voice mobile data collection, the person time and cost savings associated with avoiding round-trip public or private transit through mobile data collection could have been attributed to either the study coordinator or the study participants. Cost calculations for avoiding such travel did not account for the value of person time, and while the direct costs to mobile phone follow-up were slightly higher than the cost of having the participants take public transit to interview, the cost estimates did not include the value of the participant's time or the additional interviewer time and airtime that would have been required for scheduling these interviews, both of which are estimated to be substantial. Furthermore, because no participants reported having their own phones prior to being given phones to participate in the study, it would have been much more difficult to coordinate follow-up data collection, and greater incentives would have had to be included for the larger travel and time burden to maintain participant retention. The alternative scenario of the interviewer traveling to capture participant data would have incurred more significant person-time costs and incur higher interviewer-related expense.

Our findings suggest that the use of lower technology voice-to-voice data collection served a further purpose, providing a highly positive effect on women's perceptions of support in the post-surgical period. Social support has previously been identified as an important component leading to social reintegration among women affected by fistula (Ahmed & Holtz, 2007; Pope et al., 2011) and improved recovery and survival for individuals with other conditions (Casale, 2015; Reblin & Uchino, 2008). The research team did not consider using computer-assisted data collection programming due to concerns around familiarity of the target population with smart phone technology; however, other projects targeting rural or otherwise

geographically dispersed populations may consider how social support provision via voice-to-voice and SMS mobile technology may enhance health research or programming efforts; however, the potential for social desirability bias may be higher with this method due to direct contact with the interviewer and due to the research team's provision of mobile phones to the participants

In conclusion, voice-to-voice data collection was a feasible, acceptable, and inexpensive method to conduct longitudinal follow-up for self-report in this study of a geographically dispersed female patient population in Uganda. Future research may benefit from the high retention rate obtainable *via* this data collection modality, and future programming should take advantage of the potential for mobile social support for improving patient recovery experiences.

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Disclosure statement

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