



Uncovering Inequitable Access to Vaccination Programs by Nomadic Bedey Children of Bangladesh

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**UNCOVERING INEQUITABLE ACCESS TO VACCINATION PROGRAMS BY
NOMADIC BEDEY CHILDREN OF BANGLADESH**

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A Thesis Submitted to the Faculty of
The Harvard Medical School
in Partial Fulfillment of the Requirements
for the Degree of Master of Medical Sciences in Global Health Delivery
in the Department of Global Health and Social Medicine
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Abstract

Vaccination coverage gaps in children across geographic^{1,2,3} and ethnic lines exist in Bangladesh. To address this vaccine-divide, the study evaluates whether the current approaches to vaccine-delivery is reaching communities, like the Bedey—an ethnic-minority and once primarily river-dwelling nomadic group—who are highly mobile and have a unique socioeconomic, political, cultural, and historical background.

A convergent mixed-methods study was conducted. The cross-sectional survey measured vaccination coverages of Bacille Calmette Guerin (BCG), Pentavalent (DPT, Hepatitis B, Hib), Oral Polio Vaccine (OPV), Pneumococcal Conjugate Vaccine (PCV), Inactivated Poliovirus Vaccine (IPV) and Measles and Rubella (MR) among Bedey and non-Bedey children of ages 0-10 years in Dhaka and Barisal division of Bangladesh from October through December 2018. Vaccination coverage data were collected from vaccine cards, verbal recall, or both sources. The qualitative study explored challenges and facilitators of Bedey communities in accessing vaccination programs through field observations, in-depth and semi-structured interviews of key informants.

A total of 208 Bedey and 161 non-Bedey children of ages 0-10 years were enrolled to assess age-appropriate routine vaccination coverage. Overall, only 52% (109/208) of the Bedey children received one dose of BCG compared to 96% (155/161) of the children in the non-Beday

comparison group. In the multivariable logistic regression, it was found that the odds of having unreached children in Bedey community were much higher compared to the comparison group after being adjusted for parent, household and child-specific characteristics (OR=10.64, 95% CI: 3.49-32.44, p-value < 0.0001).

In the qualitative study, 42 Bedey community members and 7 vaccine service providers participated. Data from this study suggest that a lack of guidelines in categorizing a child as “outsider” vs. “local,” requirements of a child to stay long in an area to avoid dropouts, misinformation about vaccines and their benefits, the Bedey community’s social isolation, and a failure to recognize them as a community all contribute to this low immunization coverage.

In conclusion, current approaches to childhood vaccinations are falling short of reaching the Bedey community in Bangladesh. The study results highlight the importance of having tailored vaccination programs for the Bedey reflecting their unique socioeconomic, political and cultural contexts.

For my father, who inspired me to follow my dreams.

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Introduction

In an effort to reduce vaccine-preventable diseases by the year 2020 and beyond, the global health community came together in 2010, and declared 2011-2020 a Decade of Vaccines with a vision “of a world in which all individuals and communities can enjoy lives free from vaccine-preventable diseases.”⁴ To achieve this vision of delivering universal access to existing vaccines by all regardless age, sex, gender, religion, socioeconomic status, or any other factors, a framework—the Global Vaccine Action Plan (GVAP)—was developed and endorsed by 194 Member States of the World Health Assembly in May 2012.⁵ It is now almost the end of the Decade of Vaccines. According to the 2018 Assessment Report of the Global Vaccine Action Plan, 113 countries introduced new vaccines and an additional 4.6 million infants received vaccines in 2017 compared to 2010.⁶ Universal access to immunizations is being championed by donor countries and charitable foundations such as the Bill & Melinda Gates Foundation, because immunization is recognized as being one of the most cost-effective interventions in medical sciences. Despite all the support and much progress, most of the targets set by GVAP will not be met by the end of 2020.⁶ In the midst of this high tide of support and a mix of success and setbacks of the vaccination programs, my thesis explores what universal access to immunizations looks like in the context of a historically marginalized and stigmatized population in Bangladesh.

Expanded Programme on Immunization (EPI) was launched in Bangladesh in 1979, but full vaccination coverage among one-year-old children was estimated to be only 2% in the 1985 survey.⁷ Since then, Bangladesh came a long way to achieve the vaccination coverage of 82 %⁸ by 2016 (valid full vaccination coverage by age of 12 months), with a total number of 3,138,712 children under 12 months of age.⁹ However, Bangladesh has not reached its target of 90% full vaccination coverage at the national-level and 85% in all districts.⁸ Moreover, vaccination

coverage gaps in children across geographic^{1,2,3} and ethnic lines exist. According to the Bangladesh Demographic and Health Survey 2014, Sylhet is the lowest performing division with only 61% coverage.³ In a separate study, only 57% of the children in the low-lying rural areas of Sylhet were found fully immunized as compared to 71% national coverage at the time of the study.¹ Timely vaccination coverage in infants was found to be as low as 19% in Gaibandha and Rangpur districts.² Unless the existing coverage gaps in children are properly addressed, benefits of vaccination would only be extended disproportionately to the majority population, which would broaden the gaps in infectious disease burden and inequity in child mortality that currently exists.³ To address this vaccine-divide, an ethnic-minority and once primarily river-dwelling nomadic group, the Bedey, is uniquely suited to serve as a model for highlighting the importance of having tailored vaccination programs that reflect their unique social, economic, political, and cultural contexts. Although vaccination coverage among Bedey children is far below the national average of 82 %⁸, no reliable data exist in the absence of a study primarily focusing on Bedey children. My thesis addresses this knowledge gap to bring equity in vaccination programs to Bangladesh.

Overall success of the current health programs, such as the Expanded Programme on Immunization (EPI), have impacts on a large number of people in the country; nonetheless, it does not ensure that vulnerable populations, such as ethnic minorities, are equally benefited from these programs. Their health care seeking behavior and health care accessibility could be similar, yet, quite different than the majority of the population. In order to develop and implement equitable immunization programs to overcome the existing vaccination coverage gaps in children across geographic,^{1,2,3} and ethnic lines, stakeholders in charge of policy-making and implementation, such as donor agencies, national program manager, civil surgeons, and EPI

staff, need to acknowledge the country's diverse populations and consider their unique historical and social context. They need to examine:

1. How accessible are these routine vaccination programs to the most vulnerable populations of the country?
2. Is there any particular geographic region of the country, or a particular community or an ethnic minority group being neglected?
3. How can the government maintain the success of the routine vaccination programs while expanding it to those identified as the most vulnerable populations in the country that are being left out?

To answer these questions, the first step should be to revisit the predominant way of defining “accessibility” in terms of geographical accessibility, and to consider sociopolitical, cultural, and historical contexts in terms of defining vulnerable populations.

In my thesis, I studied accessibility to vaccination programs by the Bedey through a biosocial lens. I conducted a convergent mixed-methods study. A cross-sectional survey assessed vaccination coverage gaps between Bedey and non-Bedey children, aged 0-10 and coming from similar socioeconomic and geographic locations. Qualitative data uncovered the mechanisms by which social forces structure the risks of low vaccination coverage in this highly marginalized and stigmatized community. In addition to the empirical data that were collected during the field study, much effort was invested in understanding the Bedey community's unique socioeconomic, political, cultural, and historical context. Studying only the history of Bangladesh since its independence in 1971 was not sufficient to understand the plight of Bedey community.

Discriminatory policies and social context during the British colonial era of the Bengal region

shed lights on historic marginalization and stigmatization of ethnic minorities throughout several generations, and their negative impacts on access to health care programs.

Hence, the first chapter of my thesis portrays the unequal position of Bedey community in the broader society throughout the history based on information collected from literature reviews. It describes their desire and struggles for social integration, their contentious relationships with others along with their unique sociocultural and political conditions: all of which lend a biosocial lens through which to look at their accessibility to vaccination programs and factors contributing to low vaccination coverages among Bedey children. In the second chapter, I present both quantitative and qualitative findings, and methods that are being used. It describes in details about data collection, measurement, analysis, and study findings. In the third chapter, I write about the “dream-like” childhood of a Bedey mother who is the last generation in her family to be raised in boats. Here, I portray the Bedey community and their struggles for social integration based on my personal experiences, field notes, interviews, and informal conversation with the community members. I then describe the limitations, and implications of the study findings using a mixed-methods approach in chapter IV. I conclude the chapter by emphasizing the need to go beyond defining “accessibility” in terms of geographic accessibility, and to consider sociopolitical, cultural, and historical contexts in terms of defining vulnerable populations and their accessibility to vaccination programs. Only then culture-sensitive targeted interventions and policy recommendations could be proposed to improve the vaccination coverage in vulnerable populations, such as the Bedey.

Chapter I: A Biosocial Perspective on the Bedey Community's Equal Right to Vaccination Programs

In August 1947, when the British left the Indian sub-continent, it was partitioned into two independent nations based on religious lines: a Hindu-majority India and a Muslim-majority Pakistan. The eastern part of Bengal—where Bengal Muslims were concentrated—became East Pakistan in 1947. East Pakistan later became Bangladesh in 1971 after nine months of armed conflict with West Pakistan. Today, Bangladesh is one of the most densely populated countries in the world with a total population of 164.67 million in 2017.¹⁰ The country shares borders mostly with India, and some part with Myanmar. The south of the country is the Bay of Bengal. According to a report by the Bangladesh Bureau of Statistics published in 2015, about 89% of the population are Muslims, while 10% are Hindus, and the remaining about 1% are Christian and others.¹¹ Although the majority of the population identify themselves as Bengali, according to the 2011 census, Bangladesh has 15,86,141 ethnic minority or tribal population,¹² which is less than 2% of the total population. According to a report published by the International Work Group for Indigenous Affairs, there are at least 35 languages spoken by 54 indigenous peoples in Bangladesh.¹³ Yet, Bangladesh has not adopted the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), and was one of the 11 abstentions.¹⁴

In this thesis, I look at the access to vaccination programs by the Bedey community in Bangladesh through a biosocial lens. The health of the Bedey children and their rights to vaccination programs need to be seen in the context of the Bedey community's historical marginalization, which aided to perpetuate extreme sufferings in Bedey communities for generations.

Unequal position and struggle for social integration

Historically, Bengal Muslims were divided into many social classes, even though there is no official caste system in Islam. Descendants of central Asia and middle-East immigrants were considered to be the elite, and the indigenous converts, mostly from Hindu religion, were at the other end of the spectrum. Referring to the local converts, who were not socially accepted to be in the same social status as the “elite” Bengal Muslims, Rafiuddin Ahmed in his book *The Bengal Muslims 1871-1906* wrote:

In fact, they could expect little or no change in their social status, although it is generally assumed that it was primarily to avoid social discrimination inherent in the Hindu social system that many of them accepted the faith of Islam. The immigrant Muslims were hardly prepared to admit them to a position of equality.¹⁵

This historical context of the unequal position of the local converts raises the question: how much of the needs of the ethnic minorities—who are most likely the local converts—were met by the broader society throughout history? Did their circumstances change over the course of 19th and 20th century when Bengal transformed from once Hindu-majority Bengal to a Muslim-majority East Pakistan and later, Bengali-Muslim-majority Bangladesh? Were the ethnic minorities, like the Bedey community—who share the same faith with the Bengali majority but have a different way of life—more or less likely to be socially excluded?

James Wise’s book *Notes on the Races, Castes and Trades of Eastern Bengal* helps to understand how the unequal position of local converts in the Muslim society affected Bedey community’s struggle for social integration. According to him, Bedeys (*Bediyás*) were outcast Hindus who converted to Islam in the mid-nineteenth century. However, their change of faith did

not grant them an equal social status in the society with other Muslims. James Wise recorded the discriminatory treatments against Bedey in his book where he compared these discriminatory treatments against Bedey with that of the Sudra—a lower caste in Hindu religion:

The different stages through which converted Hindus pass before they gain a position of thorough equality with the old Muhammadans can be traced at the present day. The Bediyás were outcast Hindus thirty years ago, but a Mulla now ministers to them, circumcision is practised, the Ramazán fast is kept, and the regular prayers offered up; but they cannot enter the public mosque, or find a resting-place in the public graveyard. In a social point of view they are still aliens, with whom no gentle man will associate or eat. The treatment of the Chandāl by the Sūdra is in no respect more rigorous, or harsh, than that of the Bediyás by the upper ranks of Muhammadans.¹⁶

Bedey community and their unique socio-cultural context

“If I do not pass down the healing secrets to my children, they will be lost. We were born to be river nomads.”¹⁷

—Mohammad Abbas, a Bedey father of a young boy.

The Bedey community’s struggle for social integration into Bengali-Muslim society persists to date. There is a conflict between maintaining their ancestral way of living or having new socially-acceptable livelihoods to bring themselves out of poverty.¹⁷ This struggle of the Bedey community is getting prominent as more members of this once primarily river-dwelling, nomadic community are leaving their boats and settling down on land. They are now found in various locations throughout the country, living in clusters on boats—mostly anchored to riverbanks—or in settlements near rivers, with a leader (*Sardar*) in charge. They are the ethno-

medicine practitioners, meaning that they go to places and sell trinkets, cooking utensils, spices, herbal medicines, and other small items.¹⁸ They are the snake-charmers and snake-catchers.¹⁸ They have their own language called Thet or Ther.¹⁸ In “Shamanism in Bangladesh,” Anwarul Karim identified them as Muslim-traditional healers who belong to lower social strata in the community, and practice both shamanistic and herbal healing. Men perform magic and monkey shows, while many women work as female shaman and treat various diseases and conditions, like nervous and rheumatic pain. They are the snake charmers, trinket-sellers, and palmists.¹⁹ Traditionally, Bedey women are the breadwinners who are engaged in their traditional occupations that require them to be away from home for long hours, sometimes even days, weeks, or months at a time.

Bedey children travel with their families and are often expected to engage in earnings at an early age to support their families. This makes it difficult for them to remain enrolled in a traditional school system to receive formal education. A recent study, based on Bedey communities living in Narayanganj district of Bangladesh since 2010, reported 58% of the study participants are illiterate and only 40% have primary education.²⁰ Similar results of high illiteracy are found in separate studies conducted among Bedey communities living near Turag river²¹ and Savar area²² in Bangladesh. Moreover, many Bedey families live below the poverty line. The study conducted among Bedey communities living in Savar area found: average monthly income of more than two-thirds of the families is BDT 3000.00 (about \$35) or less, which is below the poverty line.²² The majority of the earnings (88%) comes from their traditional healing practices, while only about 8% comes from business and 4.0% from service.²² These results demonstrate the Bedey community’s vulnerability in the face of social modernization. On one hand, traditional school system makes it difficult for Bedey children to

remain in school and acquire skills that are necessary to move beyond their traditional work and to participate in the formal job sector; on the other, more people in the broader society are leaning towards receiving modern medicine over traditional ones. Bedey communities that are mostly dependent on their traditional healings for earning their livings are thus particularly in a vulnerable situation.

Furthermore, early marriage is prevalent in Bedey community. More than half (56%) of the Bedey community members in Narayanganj district got married between 12 to 15 years of age.²⁰ Moreover, limited access to safe drinking water and proper sanitation was found in separate studies conducted among Bedey communities living near the Turag river²¹ and the Savar area²² in Bangladesh. This lack of access to safe drinking water and proper sanitation make Bedey children more vulnerable to infectious diseases, such as diarrhea.

Health care access for ethnic minorities and nomadic populations

Bedey community and other ethnic minorities' health care seeking behavior and health care accessibility, including accessibility to vaccination programs, could be similar, yet, quite different than the majority population in Bangladesh. Since most of the published literature focused on disparities in vaccination coverages across administrative and geographic lines, little is known about access to vaccination programs by the tribal groups and other ethnic minorities in Bangladesh. For example, according to the Bangladesh Demographic and Health Survey 2014, Sylhet is the lowest performing division with only 61% coverage,³ where many of the tribal groups reside. In a separate study, only 57% of the children in the low-lying rural areas of Sylhet were found fully immunized as compared to 71% national coverage at the time of the study.¹ Timely vaccination coverage in infants was found to be as low as 19% in Gaibandha and Rangpur districts.² None of these studies collected data on ethnicities or explored access barriers among ethnic minorities and tribal groups. As a result, a vast knowledge gap exists in this area.

There is an immediacy in achieving ambitious goals at the national level that are set by immunization programs and initiatives at the global level, such as the Global Vaccine Action Plan (GVAP) and Millennium Development Goals (MDGs). Key stakeholders—involved in the decision-making process at the local and national level—need to be cognizant of unanticipated consequences of purposive action while trying to achieve these ambitious goals, as Robert Merton considers “imperious immediacy of interest” to be one of the reasons for such unanticipated consequences.²³ Well-intended interventions to increase overall national vaccination coverage to achieve some immediate “achievable” goals, without paying attention to the historical and cultural context of ethnic minorities of Bangladesh, may potentially broaden the vaccine-divide, and thus, the differential infectious disease burden that currently exists.

A study conducted among nine ethnic groups from six hill districts of Bangladesh provides evidence for needs for policy changes, and health care service-delivery design, reflecting their unique contexts.²⁴ This article explores tribal communities’ knowledge, practices, and attitudes regarding their health, accessibility of service facilities in the areas where they live, and explores the topographical, cultural and social factors, among others, that influence healthcare-seeking behavior. Based on the study findings, the authors argue that the current service-delivery system—which is mostly designed to prioritize and deliver care for the majority Bengali population—needs to be revised, taking these tribal communities’ sociocultural factors into considerations.²⁴ Even though this study is not specific to vaccination programs for tribal children, its findings support the basis for needs to consider Bedey community’s unique social, economic, political, and cultural circumstances in order to design and implement inclusive health care programs, such as vaccination programs for their children. Many of the sociocultural and economic factors identified in this study are relevant for the Bedey community, such as the cost

of service and medicine, distance to health care facilities, and respects towards their cultural differences; however, the nomadic lifestyle of Bedey poses some unique challenges. Moreover, Bedey mostly live near rivers across the country due to their traditional way of living on boats. Their proximity to rivers and lack of stable housing places them in vulnerable situations during natural calamities, such as cyclones and floods. Focusing on the challenges in delivering care in these sites would illuminate a larger lesson for emergency preparedness and health care delivery in the midst of natural disasters when river banks get flooded and low-lying lands turn into islands. This would potentially save hundreds, if not thousands of valuable lives.

Delivering health care to the nomadic population has been a challenge in other countries as well. In an article, Debra Cohen focuses on providing health care to nomadic pastoralist population-Turkana, in the north-west region of Kenya.²⁵ She portrays the difficulties of treating diseases or conditions, like TB and malnutrition, that require several months of support. The author mentions a few of the strategies adopted by NGOs and the Kenyan government to deliver TB treatment, vaccines, and therapeutic feeding based on the Turkana's nomadic lifestyle. One strategy involves "manyatta" approach: traditional huts that are attached to health care centers where the nomads can stay and get treatments. Other strategies involve establishing health centers, with a nurse and dispensary, in large settlements of Turkana that are typically away from main roads, and across water bodies, that become inaccessible during rainy seasons. The roads and bridges to reach these settlements are rough, and are often difficult to cross even during dry seasons. This article provides insights on a few of the challenges involving delivering treatments and preventive care in the nomadic population and few strategies to overcome them, particularly when the settlement sites are hard to reach.²⁵ However, unlike Turkana settlements, many of the Bedey communities now are settled on accessible places near urban areas across Bangladesh,

like in Savar and Narayanganj. What are the reasons then for poor access to health care and vaccination coverage among Bedey communities that are settled on land and are accessible by road?

Bedey children's equal right to vaccination programs

As noted in the previous sections, Bedey is one of the most marginalized and socially isolated communities in Bangladesh. Many of them live below the poverty line, which is a known risk factor for disease and illness. Bedey children are particularly vulnerable due to lack of access to education, health care, nutritious food, safe drinking water, and sanitation. Moreover, due to early marriage practices, they often have their own families and responsibilities at very young age, and are forced to work to provide support for their families. With globalization, social changes and availability of modern technology in the broader society, Bedey are losing demand for their once much appreciated skills, traditional medicines, and their role as traditional healers. This loss of demand for their income-generating activities, without adaptation to new skills, are making Bedey communities more vulnerable to perpetuating poverty.

This seemingly unbreakable poverty cycle is a powerful social force resulting in extreme suffering for Bedey communities. Arthur Kleinman, Veena Das, and Margaret Lock write that “[S]ocial suffering results from what political, economic, and institutional power does to people and, reciprocally, from how these forms of power themselves influence responses to social problems.”²⁶ Bedey communities’ present suffering is a consequence of generational discriminatory policies toward them that could be traced back to the British colonial era. Several reports suggest Bedey were under police surveillance during the British period for their “indifferent” character²⁷ and “predatory habits”.²⁸ They were often accused of stealing whenever there was a robbery near their fleet. James Wise noted that this lack of trust in Bedey community by others was utilized by “professional thieves” who would often lay the blame on Bedeys.¹⁶ The

institutional power of the colonial government and their discriminatory policies of police surveillance facilitated social marginalization, and unequal rights of Bedey community whose legacy persists till to date. It was not until 2008 that Bedey were officially granted voting right by the Bangladesh government.

The health of Bedey children and their equal rights to vaccination programs need to be seen in this context of Bedey communities' historical marginalization, and a lack of governmental desire to provide them with equal rights, which aided to perpetuate extreme sufferings in Bedey communities for generations. Why did it take so long for the government to recognize Bedey's right to vote? How do these social and political inequalities contribute to their access to health care, particularly, Bedey children's access to routine vaccination programs? Why their sufferings are so often overlooked by the Bengali majority of Bangladesh? As Paul Farmer puts it, "[A]ny distinguishing characteristic, whether social or biological, can serve as a pretext for discrimination and thus as a cause of suffering."²⁹ Bedey communities "distinguishing characteristic"—their traditional nomadic lifestyle—is being used as a source for discrimination, and thus cause for suffering. Cultural discrimination often contributes to structural violence.²⁹ Bedey were denied to grant voting right for generations due to their nomadic lifestyle, and lack of permanent address. If a nomadic lifestyle is the reason for low vaccination coverage or poor access to health care, then why do non-nomadic Bedey communities have poor health indicators as suggested by several reports?^{20,22} Farmer argues that "[W]hen we talk about medicine or policy, a 'hierarchy of suffering' begins to take shape, for it is impossible to relieve every case at once."²⁹ In this "hierarchy of suffering," where does suffering of Bedey children fall? The suffering of those who are geographically or culturally distant from us tends to affect us less due to "exoticization of suffering."²⁹ Are we able to understand the suffering of a Bedey mother's

loss of a child from a vaccine-preventable disease? How much control does she have over health equity for her children? Paul Farmer's work showcases who gets a disease, like AIDS, and who does not is not so much dependent on the free "agent" in a setting like Haiti; rather, it is various other social forces like political, economic, and historical that are strong determinants of health.²⁹ Similarly, in a setting like Bangladesh, who has access to vaccination and who does not is influenced by such various social forces that constrain humans and inflict "structural violence" disproportionately to some communities making already vulnerable populations more susceptible to diseases.

Bedey children's right to equitable access to vaccination programs is a basic human right. To ensure their rights to vaccination programs, a strong social commitment is needed from the Bangladesh government, as well as civil society in the country. Policy-makers and national immunization program managers, local and international NGOs, donor agencies, immunization advisors from WHO and UNICEF, and other key stakeholders involved in the decision-making process need to understand the mechanisms by which various social forces are making Bedey children more vulnerable to infectious diseases than the rest of the broader society. Only then can targeted and tailored vaccination programs be developed to achieve equity in vaccination programs in Bangladesh, and thus, achieve Decade of Vaccines' vision.

Table 1: EPI vaccination schedule in Bangladesh, 2018

Diseases	Vaccine	Number of doses	Recommended age
Tuberculosis	Bacille Calmette Guerin (BCG)	1	At birth
Diphtheria, Pertussis, Tetanus, Hepatitis-B, Haemophilus influenzae-B	Pentavalent (DPT, Hepatitis B, Hib)	3	6, 10, 14 weeks
Pneumococcal pneumonia	Pneumococcal Conjugate Vaccine (PCV)	3	6, 10, 14 weeks
Poliomyelitis	Bivalent Oral Polio Vaccine (bOPV)	3	6, 10, 14 weeks
	Fractional Inactivated Poliovirus Vaccine (fIPV)	2	6, 14 weeks
Measles and Rubella	Measles and Rubella (MR)	2	9, 15 months

In this study, an ethnic-minority and nomadic group—the Bedey served as a model, and non-Bedey children living in the same administrative zone served as a comparison group. As per EPI recommended schedule (Table 1), the cross-sectional survey measured vaccination coverages of one dose of BCG, three doses of Pentavalent, three doses of OPV, three doses of PCV, two doses of IPV and two doses of MR among Bedey and non-Bedey children of ages 0-10 years in Dhaka and Barisal division of Bangladesh from October to December 2018. The qualitative part of the study explored the challenges and facilitators of Bedey communities in accessing vaccination programs through field observations, in-depth and semi-structured interviews of key informants.

Setting

Bangladesh is one of the most densely populated countries in the world with a total population of about 162.95 million in 2016,¹⁰ and the total number of children under 12 months of age was 3,138,712.⁹ The majority of the population live in rural areas while only 28% live in urban areas.³ The country is divided into 8 administrative divisions and 64 districts which are further divided into 491 sub-districts.³¹ Routine vaccines are administered at Expanded Programme on Immunization (EPI) centers and satellite clinics and on National Immunization Days.

Data were collected from 15 Bedey settlements, 3 in rural and 12 in urban areas. Of the 15 Bedey settlements, 4 were considered nomadic as the Bedey families were living in tents and boats, and the remaining 11 settlements were considered non-nomadic as the families were living in more stable housing on land at the time of the data collection. Both quantitative and qualitative data were collected simultaneously from October 2018 to December 2018.



Figure 2: Map of Bangladesh with Dhaka and Barisal division marked with star¹

¹ Source: <https://www.mapsofworld.com/bangladesh/bangladesh-political-map.html>

Quantitative study

Study population

The purpose of the study was to assess vaccination coverage gaps between Bedey children—an ethnic-minority and once primarily river-dwelling nomadic group, and comparison non-Bedey children in Bangladesh. Survey data were collected for both Bedey and non-Bedey comparison groups from the selected locations. In the Bedey group, a self-identified Bedey parent of a child ages from 0-10 years who was able to give oral consent was eligible to participate in the survey. Whereas non-Bedey parent of a 0-10 years-old child who was able to give oral consent, and lived in the same ward (administrative unit) and often within the same EPI sub-block, was eligible to participate in the survey as a comparison.

Sampling

40 settlements across 9 districts in the Dhaka division, and 13 settlements across 5 districts in Barisal division were identified with help of Bedey community leaders and the Grambangla Unnayan Committee—an NGO who worked with Bedey community in the past to improve their access to education. One rural and one urban settlement from the Dhaka division were chosen for a pilot run based on factors, such as community leaders' availability and interests. Finally, data were collected from 6 randomly selected and 9 purposively selected locations—due to their potential nomadic life—across 10 districts in Dhaka and Barisal division of Bangladesh. Of the 6 randomly selected locations, 1 was in rural, and 5 were in urban areas. Of the 9 purposively selected locations, 2 were in rural, and rest of the 7 were in urban areas.

A Bedey settlement containing about 75 households or less was mapped for a total number of eligible households and children living in that settlement. Larger settlements were

segmented into roughly about 50-75 households, and one segment was randomly chosen and was mapped for a total number of eligible households and children within that segment. Following WHO guidelines, a household was defined as a group of people who usually eat food prepared from a single cooking area.

For a comparison group, the nearest about 50 non-Bedey households located in the same ward and often within the same EPI sub-block were identified consulting with ward maps. Therefore, both comparison and Bedey households were under the supervision of the same Health Assistants in each location, and often under the same EPI outreach center. Similar to the Bedey households, the total number of eligible households and children within each segment in the comparison group were mapped. No suitable comparison households were found for one nomadic Bedey settlement as it was a temporary settlement in a field beside a university campus surrounded by university dorms and buildings under constructions.

Once a settlement and its surrounding comparison households were mapped, one household from the Bedey and one household from the comparison group were then selected by lottery, and data for all eligible children were gathered, if they had any. It was then randomly selected to either move the household numbers up or down the list to move on to the next eligible household in both Bedey and comparison group. If a household declined to participate, or was missing both parents, data were collected from the next eligible household identified from the list produced during mapping, until about 10 Bedey and 10 non-Bedey households per location were surveyed, on average.

Recruitment

Data collectors visited each Bedey settlements and talked to people informally to inform the community members and community leaders about who they were and the purpose of their study. Data collectors then sought permission to involve their community in the research. A

household's eligibility was checked while mapping the settlements by following eligibility criteria. When a house was found locked, information was collected from their neighbors or community leaders to judge that household's eligibility.

Once the households were mapped and randomized, the consent process and recruitment of Bedey parents were conducted at the household-level. An oral recruitment script in local language was used to explain the study, and the extent of their involvements. Interested parents were then officially enrolled into the study after seeking informed consent. Mothers were given preferences when both parents were present at home at the time of the survey. A waiver of written documentation of consent in the form of signatures was granted by the Institutional Review Board (IRB) of the Harvard Faculty of Medicine since the study posed no more than minimal risk to study participants and due to limited literacy among Bedey communities. Following the similar process, recruitment of non-Bedey parents were conducted at the household-level following informed verbal consent.

Data collection

A paper-based survey was used to gather information about the vaccines that are on the current vaccine schedule: one dose of BCG, three doses of Pentavalent, three doses of OPV, three doses of PCV, two doses of IPV and two doses of MR among Bedey and non-Bedey children of ages 0-10 years (Table 01). Not all children were eligible to receive all of the previously mentioned vaccines due to changes in the vaccine schedule over the past 10 years. Data were collected for the vaccines only if the children were eligible to receive them. Immunization history was obtained for all eligible children from parents' recall, and immunization record was ascertained from vaccine cards, when they were available.

All parents were asked to fill out survey questions from memory, regardless of their possession of vaccine cards. Later, they were asked to show vaccine cards, if they had any, to

collect information about their children's vaccination status on a separate section of the survey. Visual aids showing pictures of children receiving vaccines in legs, arms or shoulders were used to stimulate parents' recall. BCG scars were checked if the children were available at home at the time of the survey.

In addition to the questions related to vaccine status, the survey had questions to assess sociodemographic characteristics, disease burden and health care seeking, and parent's knowledge and access to vaccination programs. Few of the questions in the survey were unstructured, such as the ones related to a child's illness and parent's vaccine knowledge. Responses were recorded and were later grouped into categories.

Data measurement

Families who were living in tents or boats at the time of the survey were considered as nomad given their potential nomadic lifestyle, as opposed to families who were living in more stable houses on land. Parents from both groups were asked whether they ever lived in boats in their lifetime. Toilet facilities were considered improved if they had flush or pit latrines. To assess disease burden, parents were asked what happened to their children when they were sick the last time; their responses were then categorized as: common cold, cough, or fever, infectious diseases, and other or do not know.

The main goal of the quantitative study was to estimate age-appropriate immunization coverage in Bedey children under 2 years of age and to assess whether Bedey children are at higher risks for low vaccination coverage compared to the non-Bedey children from similar socioeconomic and geographic locations. Vaccination coverage was measured as a proportion where numerator was the number of children who received a particular vaccine, and the denominator was the total number of children who were eligible to receive that vaccine given their age and the year they were born. The primary outcome, the number of unreached or zero-

dose children were defined as someone who never had a single dose of vaccines. Parents who claimed their children received only oral polio vaccine and never had any injections or vaccine cards were also considered as “unreached” to reduce bias since some parents considered orally administered Vitamin-A capsules as vaccines. Following Bangladesh EPI Coverage Evaluation Survey 2016, fully immunized child (FIC) was defined as one who received one dose of BCG, three doses of Pentavalent, three doses of OPV, and one dose of MR.⁸

Parents were considered “young” if they were 25-years-old or less. Parents’ education was assessed as received no formal education or received a formal education. Parents’ vaccine knowledge was assessed by asking what vaccines are, and the responses were later categorized as either considered vaccines good for their children or did not know what they were. Parents were asked where were the nearby vaccine centers, and their responses were later categorized as either they knew or did not know. Wealth was measured in terms of floor, wall, and roof components, possession of cell phones and watches, and a number of sleeping rooms that a household had. Children were considered young if they were 60-months-old or younger.

Data analysis

Descriptive analysis of sociodemographic characteristics, disease burden and health care seeking, vaccination coverage and parents’ knowledge and access to vaccination programs were conducted where categorical variables were reported as frequencies and percentages. Not all children were eligible to receive all of the vaccines that are in the current vaccine schedule due to changes over the past 10 years. Therefore, anyone born in January 2012 or after were considered eligible to receive the 2nd dose of measles, and anyone born in January 2015 or after were considered eligible to receive three doses of PCV and the 1st dose of IPV. For the 2nd dose of IPV, only children who were born in January 2018 or after were considered eligible.

The proportion of vaccinated children, overall and by vaccine type, were recorded, drawing on several data sources: vaccine cards, verbal recall, or both sources. Denominator for “vaccine card” section was only the eligible children who had vaccine cards, the denominator for the “verbal recall” section was only the eligible children who did not have cards, and denominator for “both sources” were all eligible children regardless their vaccine card status. When a parent could not recall whether or not a child received a particular vaccine, it was considered “no” to have a conservative estimation. Moreover, when a parent said a child received a particular vaccine but could not recall how many doses, only the first dose was considered as “yes”.

Univariable logistic regressions were performed to assess associations between the individual variables and the primary outcome: unreached children. An association was considered statistically significant when the odds ratio (OR) was either greater than or less than 1 and $p\text{-value} < 0.05$. Risk factors for multivariable logistic regression were chosen based on literature review and knowledge about the particular context of the research to identify potential confounding factors. A backward step-wise multivariable logistic regression was used (Stata command: `stepwise, pr (0.20) pe (0.10): logistic y x1 x2 x3....`) to assess the odds of having unreached children in Bedey community compared to the comparison group after being adjusted for parent, household and child specific characteristics. The significance level for removal of a variable from the multivariable logistic regression was 0.20, and the significance level for addition to the multivariable logistic regression was 0.10. All statistical analysis was performed by using Stata 14.2 (College Station, TX: StataCorp LP. 2015).

Quantitative results

From October to December, 2018, a total of 369 children of ages 0-10 years in Dhaka and Barisal division of Bangladesh were enrolled to assess age-appropriate vaccination coverage of

one dose of BCG, three doses of Pentavalent, three doses of OPV, three doses of PCV, two doses of IPV and two doses of MR. Of the 562 Bedey households screened for eligibility, 32% (179/562) were excluded for not having eligible children in the households, or failure to confirm their eligibility; of the 681 comparison households screened for eligibility, 41% (278/681) were excluded for not having eligible children in the households, or failure to confirm their eligibility. In the Bedey group, 25% (142/562) of the households were randomly selected; and data were collected for 208 children. Whereas in the comparison group, 18% (125/681) of the households were randomly selected; and data were collected for 161 children. In total, 51 Bedey and 96 comparison children had vaccine cards. For the rest, vaccination data was collected only from parents' memory (Figure 1).

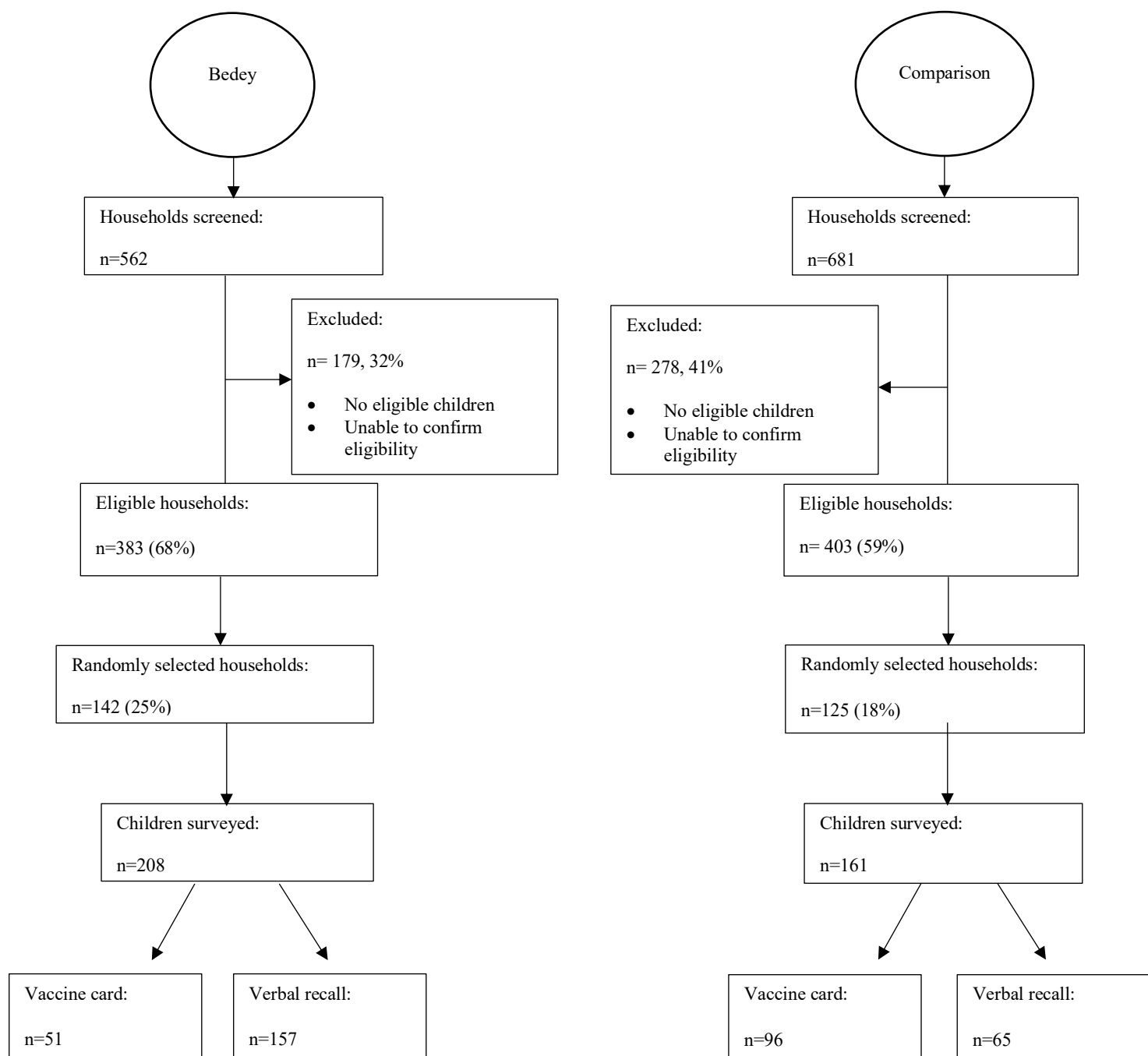


Figure 3: Selection of eligible Bedey and comparison households and children

Sociodemographic characteristics were collected and analyzed at the household level. 54% (77/142) of the Bedey households lived in houses and the rest lived in boats, tents, macha (mostly bamboo made structures on raised platform), or dera (made with boat roofs). Whereas 100% (125/125) of the comparison households lived in houses, and none lived in boats or tents. 50% (71/142) of the Bedey parents either lived in boats previously, or were living in boats at the time of the interview; in contrast, none of the comparison parents, ever lived in boats. Mothers' education was particularly low among Bedey. 68% (97/142) of the Bedey mothers never had formal education, compared to only 13% (16/125) of the comparison mothers. Mothers' education was least among rural Bedey mothers. Only 3% (1/30) of the rural Bedey mothers had formal education, as opposed to 96% (26/27) of the rural comparison mothers. However, the proportion of Bedey mothers engaged in income-generating activities was higher than comparison mothers. 48% (67/141) of the Bedey mothers were engaged in income-generating activities at the time of the interview, in contrast to only 7% (9/125) of the comparison mothers. While 12% (17/142) of the Bedey households did not have access to improved toilet facilities, all the comparison households had access to improved toilet facilities (Table 2).

Table 2: Baseline characteristics of Bedey (n=142) and comparison (n=125) households in Bangladesh, 2018

Characteristics	Attributes	Rural Bedey n (%) or median	Rural comparison n (%) or median	Urban Bedey n (%) or median	Urban comparison n (%) or median	Total Bedey n (%) or median	Total comparison n (%) or median
Live where	Boat or tabu	13 (43%)	-	24 (21%)	-	37 (26%)	-
	Matcha or dera	3 (10%)	-	25 (22%)	-	28 (20%)	-
	House	14 (47%)	27 (100%)	63 (56%)	98 (100%)	77 (54%)	125 (100%)
Years in home (median)		8	9	10	8	10	8
Ever lived in boat	Yes	25 (83%)	-	46 (41%)	-	71 (50%)	-
	No	5 (17%)	27 (100%)	65 (59%)	98 (100%)	70 (50%)	125 (100%)
Mother's education	No formal education	29 (97%)	1 (4%)	68 (61%)	15 (15%)	97 (68%)	16 (13%)
	Formal education	1 (3%)	26 (96%)	44 (39%)	83 (85%)	45 (32%)	109 (87%)
Father's education	No formal education	20 (67%)	1 (4%)	55 (49%)	15 (16%)	75 (53%)	16 (13%)
	Formal education	10 (33%)	24 (96%)	57 (51%)	80 (84%)	67 (47%)	104 (87%)
Mother's employment	Unemployed	6 (20%)	24 (89%)	68 (61%)	92 (94%)	74 (52%)	116 (93%)
	Employed	24 (80%)	3 (11%)	43 (39%)	6 (6%)	67 (48%)	9 (7%)
Household members (median)		4	4	5	4	4	4
Source of drinking water	Tap	-	3 (11%)	16 (14%)	32 (33%)	16 (11%)	35 (28%)
	Tubewell	28 (93%)	24 (89%)	88 (79%)	66 (67%)	116 (82%)	90 (72%)
	Surface water	2 (7%)	-	8 (7%)	-	10 (7%)	-
Toilet facility	Improved, shared	19 (63%)	6 (22%)	74 (66%)	47 (48%)	93 (65%)	53 (42%)
	Improved, not shared	5 (17%)	21 (78%)	27 (24%)	51 (52%)	32 (23%)	72 (58%)
	Not improved or no facility	6 (20%)	-	11 (10%)	-	17 (12%)	-
Access to mobile phone	Yes	30 (100%)	27 (100%)	107 (96%)	97 (99%)	137 (96%)	124 (99%)
	No	-	-	5 (4%)	1 (1%)	5 (4%)	1 (1%)

Table 3: Disease burden and health care seeking of Bedey (n=208) and comparison (n=161) children in Bangladesh, 2018

Characteristics	Attributes	Rural Bedey n (%)	Rural comparison n (%)	Urban Bedey n (%)	Urban comparison n (%)
Place of delivery	Home	45 (100%)	25 (68%)	136 (83%)	67 (54%)
	Non-home	-	12 (32%)	27 (17%)	57 (46%)
Facility where a sick child receives care	Only government	-	1 (3%)	6 (4%)	5 (4%)
	Only private	-	3 (8%)	3 (2%)	15 (12%)
	Only pharmacy	18 (40%)	4 (11%)	56 (35%)	15 (12%)
	Government with others	18 (40%)	29 (78%)	74 (46%)	49 (40%)
	Private with pharmacy	9 (20%)	-	22 (14%)	39 (31%)
	Other	-	-	-	1 (1%)
Person accompanies sick child to a facility	Only parents	37 (82%)	31 (84%)	143 (89%)	115 (93%)
	Family members are involved	8 (18%)	6 (16%)	18 (11%)	9 (7%)
When did a child got sick last time	≤3 months	29 (64%)	36 (97%)	141 (88%)	110 (89%)
	3+ to 6 months	5 (11%)	1 (3%)	4 (2%)	5 (4%)
	6+ months	4 (9%)	-	1 (1%)	3 (2%)
	Never got sick or don't recall	7 (16%)	-	15 (9%)	6 (5%)
What happened to a sick child last time	Common cold, cough, fever	32 (74%)	32 (86%)	132 (84%)	112 (90%)
	Infectious diseases	8 (19%)	1 (3%)	13 (8%)	7 (6%)
	Other/don't know	3 (7%)	4 (11%)	13 (8%)	5 (4%)
Children ever died in a household	Yes	10 (33%)	5 (19%)	14 (13%)	11 (11%)
	No	20 (67%)	22 (81%)	97 (87%)	87 (89%)

Facility-based delivery was low in both Bedey and comparison households. 100% (45/45) of the rural Bedey children and 83% (136/163) of the urban Bedey children were born at home. Whereas among the comparison children, 68% (25/37) of the rural and 54% (67/124) of the urban comparison children were born at home. Dependence on pharmacy for seeking care is particularly high among Bedey households. 40% (18/45) of the rural Bedey and 35% (56/161) of the urban Bedey households identified pharmacy to be the only place where they seek care when children are sick. Majority of the children in all four groups, 64% (29/45) of the rural and 88% (141/161) of the urban Bedey children, and 97% (36/37) of the rural and 89% (110/124) of the urban comparison children; were sick within the past three months prior to the time of the interview; most frequent causes of illness were common cold, cough and fever (Table 3).

Table 4: An age-appropriate vaccination coverage analysis for Bedey (n=208) and comparison (n=161) children age 0-10 years in Bangladesh, 2018

Group	Bedey n(%)	Comparison n(%)	Bedey n(%)	Comparison n(%)	Bedey n(%)	Comparison n(%)
	Vaccine card		Verbal recall		Both sources	
Vaccines						
BCG	50 (98%)	95 (99%)	59 (38%)	60 (92%)	109 (52%)	155 (96%)
Penta ≥ 1	48 (94%)	96 (100%)	55 (36%)	57 (89%)	103 (51%)	153 (96%)
PCV≥ 1	26 (93%)	43 (96%)	20 (33%)	13 (93%)	46 (52%)	56 (95%)
OPV≥ 1	48 (94%)	93 (97%)	53 (35%)	58 (91%)	101 (50%)	151 (94%)
IPV≥ 1	20 (71%)	28 (62%)	18 (30%)	13 (93%)	38 (43%)	41 (69%)
MR≥ 1	31 (72%)	71 (85%)	37 (26%)	51 (80%)	68 (37%)	122 (82%)
All vaccines	30 (68%)	68 (80%)	1 (1%)	1 (2%)	31 (17%)	69 (46%)
Unreached	1 (2%)	-	95 (61%)	5 (8%)	96 (46%)	5 (3%)
Total children	51	96	157	65	208	161

n= number of children who received a particular vaccine; all vaccines is defined as one dose of BCG, three doses of Pentavalent, three doses of OPV, and one dose of MR; unreached is defined as a child who never received any vaccines.

Table 5: An age-appropriate vaccination coverage analysis for Bedey (n=208) and comparison (n=161) children age 0-10 years by rural and urban location in Bangladesh, 2018

Group	RB n(%)	RC n(%)	UB n(%)	UC n(%)	RB n(%)	RC n(%)	UB n(%)	UC n(%)	RB n(%)	RC n(%)	UB n(%)	UC n(%)
	Vaccine card				Verbal recall				Both sources			
Vaccines												
BCG	6 (100%)	20 (100%)	44 (98%)	75 (99%)	10 (26%)	16 (94%)	49 (42%)	44 (92%)	16 (36%)	36 (97%)	93 (57%)	119 (96%)
Penta ≥1	6 (100%)	20 (100%)	42 (93%)	76 (100%)	8 (21%)	13 (76%)	47 (41%)	44 (94%)	14 (32%)	33 (89%)	89 (56%)	120 (98%)
PCV≥1	2 (100%)	7 (88%)	24 (92%)	36 (97%)	2 (14%)	2 (67%)	18 (39%)	11 (100%)	4 (25%)	9 (82%)	42 (58%)	47 (98%)
OPV≥1	6 (100%)	20 (100%)	42 (93%)	73 (96%)	11 (29%)	16 (94%)	42 (37%)	42 (89%)	17 (39%)	36 (97%)	84 (53%)	115 (93%)
IPV≥1	0 (0%)	3 (38%)	20 (77%)	25 (68%)	3 (21%)	2 (67%)	15 (33%)	11 (100%)	3 (19%)	5 (45%)	35 (49%)	36 (75%)
MR≥1	5 (83%)	17 (89%)	26 (70%)	54 (83%)	2 (6%)	13 (76%)	35 (33%)	38 (81%)	7 (17%)	30 (83%)	61 (43%)	92 (82%)
All vaccines	5 (83%)	17 (89%)	25 (66%)	51 (77%)	0 (0%)	1 (6%)	1 (1%)	0 (0%)	5 (12%)	18 (50%)	26 (18%)	51 (45%)
Unreached	-	-	1 (2%)	-	28 (72%)	1 (6%)	67 (57%)	4 (8%)	28 (62%)	1 (3%)	68 (42%)	4 (3%)
Total children	6	20	45	76	39	17	118	48	45	37	163	124

n= number of children who received a particular vaccine; RB= Rural Bedey; RC= Rural comparison; UB= Urban Bedey; UC= Urban comparison; all vaccines is defined as one dose of BCG, three doses of Pentavalent, three doses of OPV, and one dose of MR; unreached is defined as a child who never received any vaccines.

Vaccination coverage data were collected from parents' memory, as well as from vaccine cards, when they were available. Data from both sources showed a high BCG coverage among the comparison children compared to the Bedey children, indicating, a large number of children in Bedey communities never received any vaccines. Overall, only 36% (16/45) of the rural and 57% (93/163) of the urban Bedey children received one dose of BCG. Whereas 97% (36/37) of the rural and 96% (119/124) of the urban comparison children received one dose of BCG. The proportion of unreached children among rural Bedey was 62% (28/45) and among urban Bedey

was 42% (68/163). In contrast, the proportion of unreached children was only 3% (1/37) among rural and 3% (4/124) among urban comparison children. Overall, 12% (5/42) of the rural, and 18% (26/143) of the urban Bedey children received all basic vaccines, defined as: one dose of BCG, three doses of Pentavalent and three doses of Oral Polio Vaccines, and one dose of MR vaccine. Whereas 50% (18/36) of the rural and 45% (51/113) of the urban comparison children received all basic vaccines (Table 5).

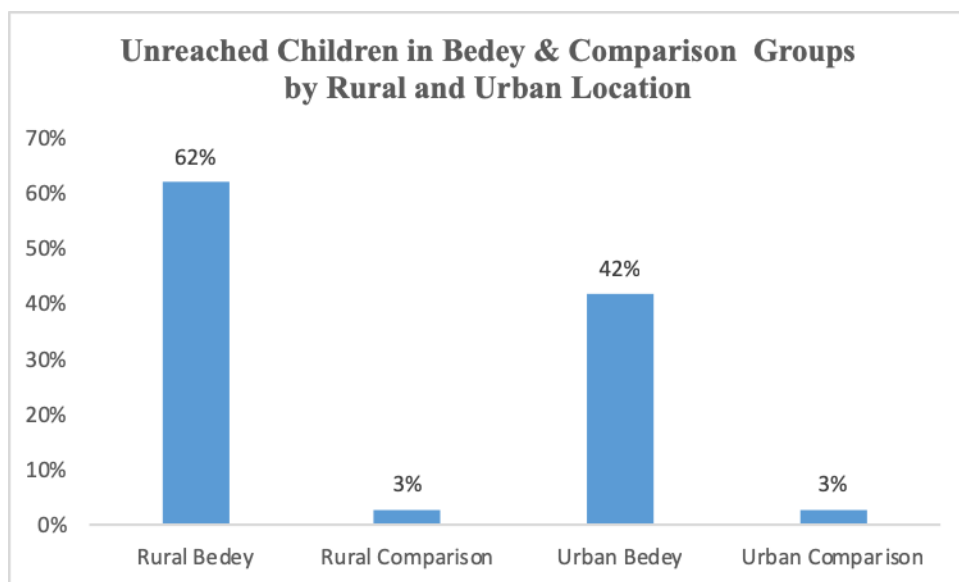


Figure 4: Proportions of unreached children by rural and urban location

Overall, the majority of the parents considered vaccines are good for their children; an even larger proportion of parents knew the location of nearby vaccine centers. Among the four groups, rural Bedey parents had the least amount of vaccine-related knowledge. Only 44% (12/27) of the rural Bedey parents knew about vaccine's benefits, and 59% (17/29) knew the location of nearby vaccine centers. Majority of the parents said they could reach the nearby vaccine centers within 30 minutes from their homes on foot. It was particularly high among both rural and urban comparison groups. Whereas of the rural Bedey households, 44% (12/27) said they did not know how much time it takes to reach a nearby vaccine center. In contrast, urban

Bedey parents had better vaccine-related knowledge. 78% (87/112) knew vaccine benefits, 86% (96/112) knew the location of nearby vaccine centers, 86% (96/112) knew transportation, and 86% (96/112) knew the time to reach to the centers (Table 6).

Table 6: Vaccine knowledge and access to vaccination programs by Bedey (n=142) and comparison (n=125) households in Bangladesh, 2018

	Attributes	Rural Bedey n (%)	Rural comparison n (%)	Urban Bedey n (%)	Urban comparison n (%)
Vaccine Knowledge	Good for health	12 (44%)	25 (93%)	87 (78%)	77 (83%)
	Don't know	15 (56%)	2 (7%)	25 (22%)	16 (17%)
Knows nearest vaccine center	Yes	17 (59%)	26 (96%)	96 (86%)	96 (99%)
	No	12 (41%)	1 (4%)	16 (14%)	1 (1%)
Transportation to nearest vaccine center	Only on foot	13 (48%)	17 (63%)	72 (64%)	72 (73%)
	With transportation	2 (7%)	9 (33%)	24 (21%)	23 (23%)
	Don't know	12 (44%)	1 (4%)	16 (14%)	3 (3%)
Minutes take to reach nearest vaccine center	≤30 minutes	15 (56%)	26 (96%)	95 (85%)	95 (97%)
	>30 minutes	-	-	1 (1%)	-
	Don't know	12 (44%)	1 (4%)	16 (14%)	3 (3%)
Head of household	Mother	3 (10%)	4 (16%)	8 (7%)	7 (7%)
	Father	26 (87%)	18 (72%)	88 (80%)	84 (86%)
	Others	1 (3%)	3 (12%)	14 (13%)	7 (7%)
Vaccine decision	Only parents	16 (94%)	25 (93%)	87 (87%)	86 (92%)
	Family members are involved	1 (6%)	2 (7%)	13 (13%)	7 (8%)

Table 7: Logistic regression model for vaccine coverages in Bedey (n=208) and comparison (n=161) children age 0-10 years in Bangladesh, 2018

Characteristics	Attributes	Never vaccinated unadjusted			Never vaccinated adjusted		
		OR	P-value	95% CI	OR	P-value	95% CI
Parent age (years)	≤25 vs. 25 ⁺	1.02	0.915	0.64-1.63	-	-	-
Mother's education	Some vs none	0.06	0.000*	0.03-0.12	0.29	0.002*	0.13-0.64
Mother's occupation	Employed vs. unemployed	7.87	0.000*	4.71-13.16	2.19	0.024*	1.11-4.33
Parents' vaccine knowledge	Knows vs. don't know	0.12	0.000*	0.07-0.22	0.19	0.000*	0.08-0.42
Knows the nearest vaccine center	Knows vs. don't know	0.12	0.000*	0.06-0.24	0.53	0.170	0.22-1.30
Residence	Urban vs. rural	0.61	0.067	0.36-1.03	-	-	-
Group	Bedey vs. comparison	26.74	0.000*	10.54-67.86	10.64	0.000*	3.49-32.44
Lived in boat	Yes vs. no	5.80	0.000*	3.50-9.59	-	-	-
Wealth quintile	Richer vs. poorer	0.33	0.000*	0.18-0.59	0.32	0.007*	0.14-0.73
Place of birth	Home vs. non-home	5.68	0.000*	2.64-12.22	-	-	-
Child sex	Male vs. female	1.17	0.498	0.74-1.86	1.63	0.147	0.84-3.17
Child age	Younger vs. older	1.14	0.568	0.72-1.81	-	-	-

* An association was considered statistically significant when the OR was either greater than or less than 1 and p-value < 0.05. Significance level for removal of a variable from the multivariable logistic regression was 0.20, and significance level for addition to the multivariable logistic regression was 0.10.

Univariable logistic regression found mother's education (OR = 0.06, 95% CI: 0.03-0.12, p-value < 0.0001), household's wealth (OR = 0.33, 95% CI: 0.18-0.59, p-value < 0.0001), parent's vaccine knowledge (OR = 0.12, 95% CI: 0.07-0.22, p-value < 0.0001) and parent's knowledge about the nearby vaccine centers (OR = 0.12, 95% CI: 0.06-0.24, p-value < 0.0001) were negatively associated with unreached children. On the other hand, odds of having unreached children were higher if mothers were employed (OR = 7.87, 95% CI: 4.71-13.16, p-value < 0.0001), and if parents lived on boats (OR = 5.80, 95% CI: 3.50-9.59, p-value < 0.0001).

In addition, children from Bedey communities (OR =26.74, 95% CI: 10.54-67.86, p-value < 0.0001), and children born at home (OR =5.68, 95% CI: 2.64-12.22, p-value < 0.0001) were also found to be positively associated with unreached children (Table 7).

In the backward step-wise multivariable logistic regression, it was found that the odds of having unreached children in Bedey community were much higher compared to the comparison group after being adjusted for parent, household and child-specific characteristics (OR=10.64, 95% CI: 3.49-32.44, p-value < 0.0001). Characteristics that remained negatively associated with unreached children after being adjustment are: mothers' education (OR =0.29, 95% CI: 0.13-0.64, p-value=0.002), wealth (OR =0.32, 95% CI: 0.14-0.73, p-value=0.007) and parent's vaccine knowledge (OR =0.19, 95% CI: 0.08-0.42, p-value < 0.0001). Whereas after being adjustment, mother's employment (OR =2.19, 95% CI: 1.11-4.33, p-value=0.024) was found to be positively associated with unreached children. However, neither parents' nor children's age, or, place of residence was found to have statistically significant association with unreached children in both univariable and multivariable logistic regressions (Table 7).

Qualitative study

Goals for the qualitative part of the study were to explore the challenges and facilitators of Bedey communities in accessing vaccination programs for their children. Therefore, qualitative data were collected for Bedey through field observations, in-depth and semi-structured interviews of key informants. Inclusion criteria for Bedey parents were the same as the cross-sectional surveys: a self-identified Bedey parent of a child aged 0-10 years who was able to give oral consent was eligible to participate in the semi-structured interviews. Community leaders and other key members participated in in-depth or semi-structured interviews. To understand the service delivery challenges, vaccine service providers: vaccinators, medical

technologists, program manager, and NGO staff, participated in semi-structured interviews (Table 8).

Table 8: Study population and their involvement in the qualitative study

Participant groups	Eligibility criteria	Participant's involvement	Number of participants
Group 1: Bedey parents	<ul style="list-style-type: none"> - Self-identified as Bedey - Parent of a 0 to 10 years-old child - Able to provide informed oral consent 	Semi-structured interviews	Bedey parents: 29
		In-depth interviews	Bedey parents: 3
Group2: Bedey community members	<ul style="list-style-type: none"> - Self-identified as Bedey - Able to provide informed oral consent 	In-depth interviews	Community leaders: 5 Community members: 2
		Semi-structured interviews	Community members: 3
Group 3: Key stakeholders	<ul style="list-style-type: none"> - EPI staff and other vaccine service providers - Able to provide informed consent 	Semi-structured interviews	EPI staff: 6 NGO staff: 1

Sampling

Bedey parents were purposively selected so the data represents views of both nomadic and non-nomadic Bedey parents from urban and rural areas of vaccinated and unvaccinated children. Some of these parents also participated in the cross-sectional surveys. Bedey community leaders from each settlement were identified either on the first day at a particular settlement or were identified beforehand with the help of a key Bedey informant. Selected Bedey community leaders and members were asked to participate in the study based on their potential to provide in-depth information on the lived-experience of being Bedey, and how this affects their access to formal medical services, including vaccinations. Vaccine service providers were purposively selected for interviews, so data represents views of actors at various levels of the vaccine delivery service, such as vaccinators—who are responsible for vaccinating children at outreach centers, and therefore, are in direct contact with Bedey communities, as well as their

supervisors and program manager at the sub-district and national level. Service providers from both high and low vaccine coverage areas were included in the study to gather comprehensive perspectives on vaccine delivery challenges and successes among Bedey children.

Recruitment

The interviewer visited each Bedey settlements and talked to people informally to inform the community members and leaders about the purpose and procedures of her study. Permission was sought from the community leader for each settlement before approaching individual Bedey parents. Consent and recruitment of Bedey parents were conducted at the household-level. An oral recruitment script was used to explain the study, and the extent of their involvements. While Bedey settlements were being mapped to record number of eligible households and children for surveys, community leaders and few eligible Bedey parents were asked to participate in the interviews. Interested parents were then officially enrolled into the study after providing informed consent. A waiver of written documentation of consent in the form of signatures was granted by the Institutional Review Board (IRB) of the Harvard Faculty of Medicine since the study posed no more than minimal risk to study participants and due to limited literacy among Bedey communities. Later, purposively selected Bedey parents—identified from the surveys—were recruited for additional interviews after providing separate informed consent.

During the field observations, the EPI outreach centers or health clinics nearest to the Bedey settlements were identified. Service providers name and contact information were collected from the signboards at the outreach centers, or from their offices. They were either approached in-person at their work place, such as at the outreach centers or at the Upazilla Health Complexes, or on the phone to share the details of the research study. Interested participants were recruited in-person for the interviews after providing informed consent.

Data collection

Qualitative data were collected in forms of field observations, semi-structured and in-depth interviews of three participant groups (Table 8). Questions were adapted after initial few interviews so they were more open-ended, and easy to understand for the participants. Field observations and interviews were collected simultaneously to the surveys from October to December 2018.

Interviewer kept field notes on overall observations about the Bedey settlements, and their locations, and geographic accessibilities, as well as, observations about the community members at various community settings, such as tea stalls or other market places without disrupting their daily lives. Observations such as sizes of the settlements and their visibility from the main road, presence of non-Bedey households within or near the settlements, Bedey members' interactions with their non-Bedey neighbours at public places were also recorded among others.

Individual semi-structured and in-depth interviews were audio recorded with permission. Topics that were covered in the semi-structured interviews of Bedey parents included: their perception about modern medicine and its accessibility, knowledge and attitude towards vaccine and their accessibility, reasons for vaccinating or not vaccinating their children. Topics that were covered in the in-depth interviews of Bedey community leaders and other key members included: their lived-experience of being Bedey, relationships with non-Bedey neighbors, nomadic life and its challenges, what it means to have voting rights, their perception about modern medicine and its accessibility, knowledge and attitude towards vaccine and their accessibility. Topics that were covered in the semi-structured interviews of service providers included: service provider's roles and responsibilities, experiences in delivering services in

Bedey communities, their perception of Bedey and Bedey parents interests in vaccinating their children, challenges and achievements of their work.

Thirty-two Bedey parents, ten Bedey community members, and seven vaccine service providers participated in the interviews across 15 Bedey settlements. All the interviews were conducted by one interviewer. Majority of the interviews of Bedey parents and other community members were conducted at their homes, with few near their homes at a community setting. All but two interviews of the service providers were conducted at their work place. Of the remaining two interviews, one was conducted at a community setting near Bedey settlement, and another one was conducted at the service provider's home at his request.

All the individual semi-structured and in-depth interviews were conducted in-person in the local language, Bengali, and were audio recorded. Additional informal conversations took place between the interviewer and four service providers, and one NGO director who are knowledgeable about the subject matter. Field notes were taken during these conversations. One-time semi-structured interviews were on average about 25-30 minutes long. In-depth interviews were on average about 50-60 minutes long in each sitting.

Field observations of the Bedey settlements, as well as, observations about the community members at various community settings, such as tea stalls or other market places were kept as field notes either on a piece of paper, or in a word document on computer. The interviewer reflected her experience in each settlement and recorded her thoughts about the interviews, and about her informal conversations with the community members. She recorded her observations, such as, sizes of the settlements and their visibility from the main road, presence of non-Bedey households within or near the settlements, distance of the nearby vaccine centers, and other health facilities.

Data analysis

Audio recordings from all interviews were transcribed verbatim in Bengali and were loaded into the qualitative analysis software *Dedoose*. Out of the different approaches to qualitative content analysis, an inductive, content-analysis approach³² was used with category construction, comparison and interpretation to analyze data collected through semi-structured and in-depth interviews.

All transcripts were read by the researcher who conducted the interviews in their entirety. A subset of interviews representing Bedey parent and service provider were selected and open coded to develop a preliminary codebook. The codebook was then piloted and revised after the initial few transcripts. The final codebook was applied to code the entire set of interview transcripts using *Dedoose* qualitative analysis software.

The investigator used an inductive approach, and examined the coded data that were developed into a set of initial descriptive categories. Through iterative process preliminary categories were refined, and a final set of descriptive themes were constructed.

Field notes and interview contents that were related to understanding lived experiences of Bedey were examined to get life stories and deeper understanding of the Bedey community.

Results

Participant characteristics

Table 9: Characteristics of Bedey Parents in the Qualitative Study (N=32).

Characteristics		N (%)
Residence	Urban	26 (81%)
	Rural	6 (19%)
Settlement type	Permanent	24 (75%)
	Nomadic	8 (25%)
Live where	Boat	8 (25%)
	Tabu	2 (6%)
	Matcha/dera	6 (19%)
	House	16 (50%)
Sex	Male	3 (9%)
	Female	29 (91%)
Age (years)	≤25 years	12 (38%)
	25 ⁺ years	17 (53%)
	Missing information	3 (9%)
Education	No formal education	12 (38%)
	Some formal education	16 (50%)
	Missing information	4 (12%)
Occupation	Unemployed	14 (44%)
	Shinga/trinket seller/snake charmer	11 (34%)
	fisherman/fishmonger	2 (6%)
	Semi-skilled or unskilled labor	1 (3%)
	Skilled labor	2 (6%)
	Missing information	2 (6%)
Children	Received vaccines	14 (44%)
	Did not receive vaccines	18 (56%)

32 Bedey parents, 10 Bedey community members, and 7 vaccine service providers participated in the qualitative study. Sociodemographic information was collected only for the Bedey parents. More than three-quarters of participants (81%) are from urban areas, and one-fourth of the Bedey parents (25%) resided in settlements that are mostly nomadic in nature. One-fourth of the participants (25%) lived in boats at the time of the interview, and half (50%) had

stable housing on land. All most all precipitants (91%) were women. About half (53%) of the Bedey parents participating in the qualitative study were over 25 years old. 50% of the participants had formal education, and about half (44%) were not engaged in any income-generating activities at the time of the interview. Overall, the number of Bedey parents with at least one unvaccinated child (56%) were little more than the number of Bedey parents with vaccinated children (44%) (Table 9).

Conceptual themes

Quantitative findings show current approaches to childhood vaccinations are inefficient to reach mobile and culturally unique populations. Qualitative data uncovered factors that are contributing to this access-barriers. Three themes emerged from qualitative study that help to explain how current approaches to childhood vaccinations are inefficient to reach mobile and culturally unique populations.

I. Geography-based approaches to service delivery assumes populations are not mobile

The current vaccine delivery model relies on a geography-based approach which was constructed on an assumption that populations are not mobile. Health service providers in our study explained the current deliver model. Each ward—an administrative unit—has eight EPI sub-blocks, and each sub-block has an outreach center for the families who reside within that sub-block. Depending on the size of the ward, one or more Health Assistants (HA) are in charge of delivering vaccines in all eight sub-blocks within a single ward. Outreach sessions take place once in every four-weeks in each sub-block. HA checks the EPI register and communicates with family members, usually the day before of an outreach session, whose children are expected to receive vaccines during that session. This is called Inter-personal Communication (IPC).

This approach is insufficient to reach mobile populations as mobile children often do not reside in one place long enough to be considered as “local[s]” to a specific sub-block. Children

are considered “outsider[s]” by the service providers when they do not reside in one place for a significant time. There are two types of lists on EPI register: one for children who are considered “local,” and another one for children who are considered “non-local” or “outsider.” There are no guidelines on determining a child “local” vs. “non-local,” therefore, determination is often subjective, and relies on service provider’s judgement. In the following quote a service provider described how in the absence of guidelines he relies on his supervisor’s guidance:

It has been found that we do not have our guideline for this. Our supervisors, such as SMO (Surveillance Medical Officer), SIMO (Surveillance Immunization Medical Officer). Earlier, we had District Immunization Medical Officer (DIMO), however, now we have only Surveillance Medical Officer. If we face any problem, or if we have to know something, we ask him. We use them as guideline. We have already asked them to do so. Now it has become very old, when the yellow paper used to be used in the register. At that time, it was said that it should be written on yellow pages, only for outsiders. From then we have been writing on yellow pages. We assume that as a guideline. It is still going on by that rule.

—service provider

The most common criterion used for determining a child “local” vs. “outsider” is the length of stay of a child in an area. If a child resides in a place sufficient time to receive subsequent vaccine doses, he is considered as “local.” On the other hand, if a child is only visiting that child is considered an “outsider.” The same service provider, quoted below, explained how vaccinators question mothers to determine their children’s status as “local” vs. “non-local” for the EPI register.

Absolutely, they ask: will you leave? How long will you stay here? How many days after you will bring your child to your father-in-law's house? Now many women's husbands reside in abroad. So, married women stay more time to their mothers' homes. So, if stays long at mother's house, and [get] all vaccines, we do not bother with the permanent or temporary, we only bother with the number of vaccines, understood? Will you take all the vaccines from here? Because the children of my area are now staying in another mother's house [elsewhere]. They also write down [children's names] at that place permanently. So we ask them do you want to get all the vaccines from here? If the answer is yes, we write on white pages.

—service provider

In this approach there is an assumption that populations are not mobile and children who are considered “outsider[s]” in one place would be residing somewhere permanently, and therefore, their names will be on the “local” children list there. However, many Bedey families still have nomadic life. Some of them live on boats, while some others live in tents and move around the country to earn livings. Often children of these nomadic Bedey families are considered “outsider” by service providers, and their names go to a separate page in the EPI list. In the following quotation, the same service provider describes a scenario about what would have happened if a nomadic Bedey group comes to her catchment area and stay for a month:

Because they are wandering around, they are still kept on yellow pages. They are not being caught, suppose a group of Bedey people come into my area. Here they stayed for one month. Within this one month, we send vaccine block wise. Maybe a worker went to the block and saw a group of Bedey people are

staying there. Then he went there for IPC to ask: do you have any child? Then they said yes, they have and also have a mentality of taking vaccine but they will not stay there in next month. So we record their information on yellow pages, my staff may write that on yellow pages. Usually Bedey groups do not come to this area, but our permanent Bedey community is [name omitted]. Maybe for this reason, their information of giving vaccine are written on yellow pages. That is why they roam around; our staffs cannot get them permanently.

—service provider

Despite of their nomadic life, some nomadic families have stable houses inside Bedey settlements. These houses are often kept locked when they are unoccupied by the owners, unless extended family members live in them. Each year, nomadic families return to their homes and stay there for a few months. Often these nomadic Bedey children are considered as “outsider” in the areas where their parents’ names are enlisted in the voter list as “local[s].” When asked, a service provider explained since these children do not stay to complete vaccine doses their names go to the “outsider” list:

No, they go away for many months. I cannot record their information into my register. So if I record their name, my register book will be empty. I cannot even give one dose. It can be seen that many times I got a child, after giving vaccine, [parent] said, sister we will not stay here, we will leave. That’s all right, where ever you feel good, go to a nearby [center] with this card, [they] will give vaccines. I tell that.

—service provider

“Outsider” children are able to receive vaccines from a center as long as they are carrying vaccine cards and the center has sufficient vaccines in stock after giving priorities to the “local” children. However, responsibility of following up with these children for subsequent doses often do not fall on the service provider where they are currently staying. Therefore, mobile parents are expected to be proactive and search for nearby vaccine centers to receive vaccines from multiple locations along their way. When a child receives their first dose, they get a vaccine card that can be shown anywhere in the country to receive the subsequent doses. Parents are expected to carry this card and actively look for vaccine centers wherever they are at until their children complete vaccinations.

However, vaccine services are not always available. Vaccines are given at government hospitals and at geographically-defined outreach centers. While government hospitals provide vaccines multiple days in a week, outreach centers, that are close to the communities where Bedey reside, provide vaccines only once every four-weeks. Mobile populations do not stay long in a given place, making it difficult for some Bedey families to align their presence in a given location with the once-a-month vaccine offering. Below, a Bedey father explains why boat dwellers often miss the opportunity to vaccinate their children because vaccinators do not approach the boats, but instead rely on having boat dwellers report to vaccination centers. Proactive Bedey parents seeking to vaccinate their children may inquire where a nearby outreach center is located, only to find that the single vaccinating date has passed, or may only be held on future date when his family will have left port:

Those who live here, the neighbourhood over there no one comes from that area to this area for vaccinations. Those who left with boats think that they go from one place to another. In that place also, think that, [no one comes] to the

boats to give vaccines. [They] know from people where is vaccines given to children. If goes to that place in time then get [vaccines] else [they] give date to return in two three days later. After two three days then [vaccine] could be given but after those two three days cannot stay [there]. This is why boat people do not get vaccines.

-Bedey father

II. Ineffective messaging to mothers

Mothers are often misinformed

Some Bedey parents in our qualitative sample were knowledgeable about vaccines, and they took their children to vaccine centers according to the schedule following service providers' recommendations. Other parents that we interviewed explained that they either did not know about vaccines, or were unaware of where and how they could access these vaccines for their children. Misinformation about benefits and side-effects of vaccines and not knowing "when" to go to a center were most frequently mentioned by the participants.

Parents explained that one reason they did not actively pursue vaccinations for their children is because children were not presenting as sick, and as such, vaccination was not seen as an urgent matter. Fever and soreness at the injection site were also offered by Bedey parents as reasons to avoid vaccinations. At best, these side effects were "inconvenient," making their healthy children sick for a few days. At worst, parents explained, these side effects were a cause for concern, and threw into doubt the effectiveness of the vaccine as an effective preventative measure. As most Bedey mothers work outside home, it gets challenging for them to balance house chores and work when their children are sick at home. They fear for losing money when they miss work, or spend money on medications to manage vaccine's side-effects. A Bedey community leader explained why parents are sometimes fearful of vaccines:

[They] fear, scared, by having these are we going to close our two days' business! [Child] will have fever or sore. Who will pay for the doctor's money?

They understand that.

-Bedey community leader

Similarly, service providers in charge of vaccinations also recognize Bedey parents' fear for side-effects as a challenge for service delivery:

They did not want to give [vaccines] at first. After that, they agree for taking the vaccination. After taking a vaccine, when a child gets fever. Usually fever comes! When fever comes they will not come to take the second vaccine. No matter how many times you say, they do not agree to come back for having the second vaccination. They say that Allah has given, anything will happen. Nothing will happen if you do not vaccinate.

—service provider

Moreover, some parents are unaware of the diseases that vaccines prevent, and they sometimes over state vaccines' preventative capabilities. This expectation sometimes undermines their trust in vaccines, when they see vaccinated children getting sick from other conditions. The following quotation illustrates dilemma of a Bedey mother who gave her child the first few doses but later decided to stop since the child had to be hospitalized multiple times, and she feared vaccines might have something to do with this:

My mother-in-law gave injection to my child. After that, my child was ill for twelve months. And child was very thin and weak. Child had thirteen illness in 12 months. Cold and fever, so my mother-in-law said no need to take

[vaccines] anymore. We gave three injections before. Was admitted into hospital two or three times in a month for that child. Cold.

-Bedey mother

This mother then goes on to say children will get sick regardless of their vaccine status:

When Allah gives disease to someone, then given if vaccinated or not vaccinated. Everyone says it is good if you vaccinate, and it is bad if do not. One third [children] got vaccines, then why children need to go to the doctor? Some children have tan [difficulty in breathing], have cold even after getting vaccines.

-Bedey mother

Sometimes Bedey parents express interests in giving vaccines, but not knowing when vaccinators come to the outreach centers is a challenge for them. One Bedey mother shared her frustrations as how no one comes to alert them when vaccinators come at the nearby outreach center. This mother was fearful about vaccines at the beginning, yet she overcame her fears and took her son to the center without his father's consent. After multiple tries she failed to vaccinate her son:

R: Yes, then it is understood that they stay on the banks of the river. We go to the bank of the river and ask someone. But do not say that. If they ask someone [I hear] many families live alongside this river. Tell them we will give vaccine on this Thursday or Friday, tell them to come. Then from here we will all go and will get vaccines. But they do not even say this. Then by myself I ask around, someone can tell correct [information] someone cannot.

I: Someone can tell correct and someone cannot?

R: Yes. I go there and come back.

I: Has it happened that you went there and came back?

R: Took [my] son and came back couple of times.

I: So did you take your little one? You were afraid, did not want to give [vaccines]. Still you went?

R: Still I went. He is a man, so much work he will do. I feared his father, several times I went stealthily. Still I could not get it [vaccine] after going [there]. Once I went, said the date is gone. Another time [I] went [they] said come back on 10th. On 10th I forgot, [date] went.

-Bedey mother

Another reason mothers sometimes return from the center without vaccinating their children is when children are sick and vaccinators ask them to come back later. Mothers fail to recognize when to go back and as their children get older, they either miss the chance or decide not to go as they fear untimely vaccination may cause harm to their children.

This one did not get [vaccine] because he had strong cold when he was child. Because of cold, [they] said when cold is no more, not in this month, that month. We always gave vaccines in front of the Girls [center]. He had strong cold, this is why [they] did not vaccinate him. By doing this, he turned two years old. After one and a half years vaccines are no longer given.

-Bedey mother

Fear of children dying from vaccines play a significant role in undermining Bedey parents' trust in them. They do not seem to capture what is at play here. These parents are making the best possible choices that they can for their children after experiencing unfortunate

events. A mother of four, who vaccinated her older child but decided not to vaccinate the younger ones, explains why she and her family lost their trust in vaccines. She saw an unfortunate event where a child had seizures and died during a vaccination campaign, and as a result of this frightening episode, this mother decided that she would not vaccinate her children in an effort to protect them from a similar fate.

First child got vaccine. Did not give vaccines to the next child out of fear. The older son got vaccine, the middle son did not get vaccine. Feared a lot. Suppose, seven children died together after taking polio vaccine. Because of that fear did not gave vaccine [orally] to children anymore. Not even injection.

-Bedey mother

She then goes on to describe her experience in great details:

No, I saw that with my own eyes. That means, I went with my child to vaccinate, the older one got it. Then I took the child, the son after the older one. [They] have [vaccines] to many, means, I was towards the end [of the line]. After having vaccine, [people] made hustle at the top of the house. [They] gave [vaccine] at the top [floor]. Then [people] asked: what happened? what happened? [Someone] said that soon after giving vaccine to someone [child] got convulsions. That polio, isn't it given orally? That one?

-Bedey mother

Rather than allay the significant fears that the episode created, the government offered financial compensation, which was viewed by the community as a paltry response to the deep emotional loss of a child.

To eat, that one was red. While having it [child] got convulsions. Then together could not take [the child] to hospital. [Child] died. Those who had it earlier inside the room they died. Those who were given later, think, did not have it out of fear. Those who gave it were detained. From where did you get this vaccine? You came to kill people. We together detained those who came to give [vaccine]. No longer gave polio vaccine. Then a big boss came from the place where they came from, doctors also came. After [they] came, gave some money to those whose children died. We said we do not need money. Give [back] our children. Would money call us mom dad? Money will not call us [mom dad]. Return our children. Then they said what has happened already, can we do [return] that? Can't do, we will file case from the government. We will go, go to the government to ask. Why [they] gave our children rejected medicine and why the child died. After that we no longer give vaccine.

-Bedey mother

The considerable fear that the community held after witnessing children who were believed to die after receiving vaccines has created a strong anti-vaccine sentiment. Another Bedey mother from a different settlement explains that in order to avoid a similar fate, she has decided not to vaccinate her children. When vaccinators approach her, she is able to send them away by reporting that her children have already been vaccinated.

R: In the past [they] came to our area and we got vaccine.

I: Area meaning, came to [name omitted]?

R: Yes, did not give to these two because so many children die after having vaccine on the roads. We see that when we go to village [work]. For that

reason, out of fear did not feed or give anything.

I: I know little about this. What do you see when you go [there]? What did you see then?

R: Given to so many children on the roads, many children die after having this vaccine.

I: They die after having vaccine? Okay, the oral one or the injection one?

R: The oral one.

I: You have seen [children] died after having the oral one? Because of this were the other mothers scared?

R: I saw this. For this reason, we do not give it [vaccine]. [We] say we gave this when [vaccinators] come.

-Bedey mother

Some of the Bedey parents regained their trust. The mother—who experienced the unfortunate event at a vaccine center—now wants to vaccinate her new born. When asked how she overcame her fear, she replied: “[I] got rid of fear because for many years [I] no longer see that. [It] looks good now. Gave [vaccine cause] saw well.” However, not everyone regained their trust in time. While some others, lost their trust in government facilities, go to private facilities and pay service fees:

We go there, give 50 taka, [they] give vaccine to us and talk good to us. Date goes by [medicine expires]? Will not kill children for 50/100 taka. Do you understand that?

-Bedey community member

Mothers often lack decision-making power

Interview participants noted that a child's wellbeing was viewed as the responsibility of his or her mother. Bedey mothers assumed responsibility for childhood vaccinations because it fell under the definition of a child's health and well-being. While the responsibility for a child's well-being was borne by mothers, these same mothers lacked the decision-making power to decide whether her child could be vaccinated. The power to make these decisions fell to husbands, or in some cases, in-laws. Some women explained that they had to submit to the wishes of a husband or in-law even if it was against their better judgement, because they feared retribution if they did not submit to a husband or in-law's decision. This is evident from the following remark by a mother who showed courage for one child but failed for another one when her husband threatened to leave her if something bad happens to their children as a result of vaccination:

I gave [vaccine] with courage. Did not give to this one out of fear for his father. [He] said that if something happens to my child, [I] will leave you, get you out [divorce], for this fear.
-Bedey mother

In-law's influence can either act as a facilitator or as a barrier. Some knowledgeable mothers-in-law provide support in various ways, such as by providing information or by accompanying mothers to the vaccine center, as evident by the following quotation of a Bedey grandmother:

[I] gave my grandchild five injections, not at home. From the age of one and a half months, taking to [name omitted] clinic. Arranged marriage with grihostho daughter. Daughter-in-law does not understand. I brought grandchild when he was one month old. Brought back [when] turned one and a half month. I went in hurry to accompany [her] to give vaccines. I showed

her (daughter in law) the ways, if I die, do like this. You also became mother of a boy. I am almost dead, we are diabetic patients. Today I am alive not tomorrow. Have kidney problem, [have] diabetics. Today [I] am alive not tomorrow. Die when [I] sleep. The road that I taught, you should do like this.

-Bedey grandmother

Some others, particularly those who did not vaccinate her own children and lack trust in vaccines, create obstacles for Bedey mothers. Here, a young Bedey mother explained how her mother-in-law's views towards vaccines influenced her husband's decision:

My mother-in-law said that we also raised seven children we did not give. Did we not raise [children]? Then our baby's [father] said that do not give [vaccine]. I said why not it is good if given, it is beneficial. [He] said our mother did not give [vaccines] to us I will also not give it to my son. For this reason [he] quarrel with me. This is why did not vaccinate child.

-Bedey mother

Bedey mothers in our study keenly felt responsible for the well-being of their children. Mothers who wanted to vaccinate their children but were unable to do so worried that when their children fell ill, it might be due to their vaccination status. The same mother who could not vaccinate her son due to her mother-in-law's influence explained her worry and concern for her unvaccinated child:

I had my own desire that if all vaccines were given to son, think that, if some disease happens today it does not matter. Previously you think if vaccines are given there is one that vaccine good for health. Now, think that, when gets cold

if something happens have to run [to a doctor] a little. For this, if vaccine was given then no need to run anymore.

-Bedey mother

Some women in our study succeeded in negotiating with their husbands. The following quote of a Bedey mother illustrates how her negotiation went with her husband and how she eventually succeeded:

I asked my husband, should [I] give vaccine [to child] or not? My husband said if you see it's good then give [it]. Or if you not see it's good, then what is the benefit to give [vaccine]? Then I said to my husband that it is good to give. I heard from ten more people. [He said] if it is good to give then you give [vaccine]. I have no problem. With my husband's permission, gave vaccines to [my] child.

-Bedey mother

Moreover, mothers are members of the broader Bedey community, and Bedey community members often get influenced by each other's opinion, and sometimes they make decisions together. A Bedey father explains how this community bonding can affect access to vaccines. If someone in their community say something good about vaccines, everyone else will have favorable view towards it. On the other hand, if someone says something bad, nothing can change their minds about it:

If one of us says that it is good then five will say the same. And if [someone says] something bad, if you say bad to a good thing, then you cannot take

[them] even if five people die. And if one person says that it is good, then 50 people or 5 people, everyone will accept it.

-Bedey father

III. Social accessibility to vaccine centers is not equivalent to geographical accessibility

EPI outreach centers are selected by health assistants at schools or at people's houses so they are physically close to individuals within a given EPI sub-block. Although Bedey leaders are willing to have centers at their houses to increase awareness and to provide better access to Bedey families, rarely outreach sessions are held in a Bedey household. The following remark of a Bedey community leader expresses their interests of having vaccine centers at their homes:

There will be no problem from our side. The Member houses that we have, this Member house, old Member house. If [someone] comes and say that [we] want to give the center here, none of us will say no. Because, what is our loss? Will come one day in a month or after 15 days. Not that many people come. If comes, our people will come. If comes, field worker comes. One or two of them come. To give vaccines. Not many people come. Two chairs are enough, nothing else is needed.

-Bedey community leader

Moreover, vaccine centers inside their settlements would provide better access to families who still live on boats and have nomadic life. Boat dwellers reside in Bedey settlements during a specific time of the year when they repair their boats. Having vaccine centers inside the Bedey settlements would provide both nomadic as well as settled Bedey families better access to vaccination programs. A Bedey mother who recently settled down on land explained how boat dwellers as well as them could be benefited from this:

No matter wherever the boat people are, in two months, in months of Chaitro and Kartic. Wherever [people] are in boats, they come here. [They] come here to stay for a month and half [to] two months. They repair boats while they stay here. They again go away to earn. If it [vaccine center] is here, they will get it [vaccine], we will get it.

-Bedey mother

However, health assistants' perceptions of Bedey settlements being unsafe and not suitable to have outreach centers actively exclude Bedey households from having EPI centers. In an interview, a Health Assistant in charge of delivering vaccines to a large Bedey settlement expressed her fear of entering into the settlement due to Bedey community members' alleged involvement with drug trafficking:

Sister, they are drug dealer, understood? Phensedyl then Yaba these, [I] am frankly telling with brother. They got involved a lot with this business. Then when [you] go to that neighbourhood you will see here and there only gambling, playing gambling. It is risky for someone to enter there. I can say this in front of him there is risk.

-service provider

While another Health Assistant in charge of a different settlement explained why she had to change outreach center location from a Bedey household. She identified lack of proper arrangements of washroom, table and chair as being reasons for relocation:

At the very beginning they used to sit there. Absolutely in the main of Bedey neighborhood. Used to sit there in the past but there is no chair, table for the

sitting arrangement. There is no system to go to the bathroom. They do not let us go [to bathroom] when we go to Bedey houses. [They say] go to that place, go that place. That is why [it] was shifted.

-service provider

Despite of Bedey community members' interests and willingness to cooperate, almost all the outreach sessions in the study area are operated in non-Bedey households or in schools. This affects Bedey children's access to vaccination programs due to lack of social integration, and often contentious relationships with their non-Bedey neighbors. A Bedey community member explained how her neighbors do not want to socially mix with them because of their heritage:

They call [us] Bedey. In this little neighborhood everyone calls us Bedey. They hang out with us very little, do not hang out much. They are the ones who call us low class, understood? What Bedey means is that they are the lowest class. That is why, those who are from good families, they do not want to hang out with us. They do not hang out with us if we want. They do not hang out, say [we are] low class.

-Bedey community member

In her case, she lives near a community clinic, and did not have to go to an outreach center at someone else's house. When asked, she replied how such lack of social integration could have affected her access to vaccines had she had to go to one of her neighbor's house:

It is actually seen that even if we could go, we would not have gone for our own reason. Maybe if [we] go to that house, someone could say something to

us. If [we] thought like this, maybe we would not have gone. But, we do not have any obstacle in going to hospital.

-Bedey community member

Sometimes Bedey feel they are being left out intentionally, particularly, in settlements where they have contentious relationships with their neighbors. They feel unwelcomed, and suspect their neighbors warn vaccinators to come inside their settlements. The following remarks by a Bedey father illustrates how he thinks hostile relationships with non-Bedey neighbors are affecting their access to vaccines:

And these house people, [vaccinator] comes up to that road to these houses. Then few grihostho say that do not go to that neighbourhood. [grihosthos] show fear. Then the vaccinators don't come to this side anymore. That's why people who are local here do not get vaccine.

-Bedey father

It will be good if it is convenient for us so we can vaccinate children. Or, that grihosthos do not prohibit [vaccinators]. So, when we go to vaccine center [they] give us properly. [They] should call us with interest and with little respect. We do not get [news] that there is vaccine in that house, you guys come.

-Bedey father

In contrast, in communities where relationships between the Bedey and non-Bedey neighbors are friendly, information about vaccines flows more freely. Non-Bedey neighbors share information about the benefits of vaccines with their Bedey neighbors, and they inform Bedey neighbors about the time and location of upcoming vaccination sessions. A Bedey mother

shared her story how one of her non-Bedey neighbors informed her about vaccines and took her with them:

Say, [I] did not understand then, my daughter was small. Then said hey my daughter also got measles. [She] was small when got measles. Then said did you vaccinate your kid? I said no. My in-laws house was in [name omitted]. I said, no [I] did not vaccinate. [They] said you should come so and so date your child should be given vaccine. Then the house that I rented, people of that house also said that give vaccine. He also had breathlessness from cold. Said give her a vaccine too. I do not understand, so much said, I will go. Take me if you go since I do not know this country. [Neighbor] said okay when I go you should come when I ask. Then I took my daughter to give vaccines.

-Bedey mother

Chapter III: Swapna and Her “Dream-like” Childhood

This chapter is based on interviewer’s field notes, formal and informal conversation with the community members, and her personal experiences.

Swapna and her life in a boat

I met Swapna on a crisp winter morning at her home on my last day in Barisal. The past few days had been hectic, and much work still needed to be done in the coming days. The long list of things that I needed to do before I was to leave Barisal in the afternoon went on in my mind like an earworm: interviews, surveys, meeting with NGO; interviews, surveys, meeting with NGO. Meanwhile, my mother was anxiously waiting for me back at the rest house, as I had yet to fulfill my promises to take her to the popular guava gardens in Jhalokathi, which were beside the countless numbers of rivers and canals that she had seen on news a couple of years back. All along this had been her secret motivation for accompanying me to Barisal, something I

realized once I reached there. Then I met Swapna. All my data collection worries and an imminent broken promise to my mother were blown away, as I listened to stories about her “dream-like” childhood in a boat. It was as if somehow Swapna and I could defy the laws of physics and travel back in time to become a part of her life journey.

I sat on Swapna’s bed, holding firmly to my recorder so I wouldn’t miss anything that my chatty interviewee had to say. A 38-year-old mother of two sons, and oldest of five siblings, Swapna is the last generation in her family to be raised in boats. She had never lived in a house before settling down on land with her family in 2000, as all her extended family members were living on boats at that time. Swapna’s father, who was a stone seller, and her mother, who performed *Shinga*—a traditional way to treat arthritis that Bedey women are known for—lived in a boat with their five children. Swapna identified herself as a *Mirshikari*. According to one of the community leaders, their ancestors used to hunt deer, wild roosters, and other animals. However, now-a-days, they are engaged in selling clothes, stones, etc. and women perform *Shinga*. The younger generations who have education, like Swapna’s siblings, are working in public or private sectors.

Swapna reminisced about her “dream-like” childhood. She and her siblings would get off the boat when it was anchored to a river bank. They would walk on land and play all day while their parents shop in the nearby *bazar*. At the end of the day, they would go back to the boat to eat and to sleep “just as birds” go back to their nests in the evening. The whole time she spoke, I kept thinking: *Is she really describing a life in Bangladesh? A country where we both grew up?* I grew up in the capital, about 190 km. north-east from where we were now; and yet, our worlds could not have been further apart.

It has been only about 18 years since she and her family had settled down on land, beside a river. Her father, uncle and grandparents had bought this piece of land together about a decade or two ago—according to her estimation—before they settled down here and built houses. Buying land close to river banks in areas that they usually call “home,” and not building houses for years is not unique to Swapna’s family. Time and time again I heard from my interviewees how their parents and grandparents bought land beside river banks where they usually anchored their boats for months but had never lived until recently when they decided to settle down. This made me wonder: why would a group of river gypsies buy land never to live on them for years, and what does belong to a village or a town mean to them?

Social structure of the Bedey

Bedey still maintain their traditional social structure in regards to where they live, travel, and work as a group, surrounded by their extended family members and other Bedey community members. Their leaders are known as *Sardar*, and Bedey strictly follow their decisions and guidance in almost every aspects of their lives. Within the *Sardar* system, there is a hierarchy; there are *Sardar* at the regional-level, at each individual settlement, and even in the small groups with couple of families when they travel together for work. In my field study, I found that I was expected to get permission from these *Sardars* before asking parents to participate in the study. Often, I was asked by Bedey community members if I had consulted with their *Sardars* before they would talk to me.

Sometimes I had to wait few hours to meet them and to seek permission, as they were away from home. In a few settlements, I talked with the community members and received permission from them instead. It was unclear who their *Sardar* was, and in one instance, I was told they don’t have a *Sardar* anymore, they just have elderly community members who they

respect and listen to. I was granted permission in all the locations where I worked, so asking for and being granted of permission was primarily a show of respect.

For the most part, Bedey still live under a *Sardar's* guidance. It seemed to me that *Sardar* play the role of a government in their lives. For generations they lived as a nomadic group, following their own customs. A Bedey *Sardar* told me that things such as marriage, divorce, property disputes are still handled by them, and their community members rarely seek legal actions outside. *Sardar* influence almost every aspect of Bedey lives, including: where and when to settle down, where to go to earn livings, which month to return to the settlements, and even whom to vote for, among others. Moreover, Bedey pay a percentage of their incomes to the *Sardar*. On the other hand, *Sardar* and their wives look after their members when they need money, food and medical treatment. This *Sardar* system is hereditary, with a *Sardar's* son becoming the next *Sardar*. He decides which one of his sons will become the next *Sardar*, considering his son's knowledge, temperament, and leadership ability.

Bedey identity and their Jajabor life

From my filed observations and interviews, I found out that who is a “nomad” and who is “settled” is not as black and white as one may think. Traditionally, Bedey lived on boats and roamed around the country. Now, only a small number of families still live on boats, and living on boats is not a reliable indicator for a family to be considered a nomad anymore. I found out that many of these families live in boats owing to their financial inability to build a home on land and not because of their tradition. In one particular settlement, most families that I talked to said they started to live in boats once their slums got destroyed by the government for some construction projects. Some of these mothers never lived in boats before but had to live now since they simply cannot afford to rent a room on land. From the surveys and interviews it was apparent that many boats never leave the location where they were at the time of the interviews.

Others, particularly fishermen, often leave and go deep in the river to catch fish and come back at the end of the day, or within few days, depending on the season or potential of catching fish.

In contrast to these families who live in boats, yet are nonnomadic, I found families with stable houses who still have nomadic lives. In these settlements, I saw locked houses because families were travelling for weeks, and often months, living in makeshift tents as nomads while they engage in their traditional occupation. From my interviews with Bedey parents and community leaders, I learned that financial constraints were one reason for these families to leave their homes. Community leaders explained that since many Bedey are still engaged in their traditional occupations that are dependent on clients, they find it difficult to earn money if they stay long in the village area where they have homes. I saw this in the settlement where Swapna lives. At the beginning only three families, including Swapna's, settled down on land. Within two decades, about 100 more *Mirshikari* families started to live there. Swapna estimated that 30-40 families were present at the time when I visited her, while the rest were away for business.

Low literacy and lack of transferrable skills force many Bedey to keep their traditional occupations. Furthermore, community leaders indicated that they do not earn as much as they used to due to reduced trust and demand for their ethno-medicines, other products and services in the broader society. Therefore, many of them lack capital, and are also unable to get microfinances. A mother once told me she had only 20 taka (\$0.25); if she were to go to work that day, she would have to use that in transportation. But she needs to feed her children, so she decided not to go. And now that she couldn't go, she missed out on the opportunity to earn. Many Bedey are in similar situations as hers, trapped in a vicious cycle of poverty.

Bedey consider their *jajabor* [nomadic] life as one of the reasons why they are looked down by the broader society. A *Sardar* told me why Bengali people call them *jajabor*: "They do

not have houses, homes, land, doors. They live in the river, what kind of life do they have? That is why they called us *jajabor*.” He dislikes the word “*jajabor*”, and considers this a derogatory term, like many others in his community, particularly because many of them have settled down on land and have voting rights now. While I was interviewing him, a young boy, most likely a teenager, commented that he gets upset when someone calls him Bedey or Mangta. This was not the first time I heard that. In some settlements Bedey community members identified themselves as Bedey or as Mangta. In others, particularly in Shandar settlements, they did not want to be called Bedey or Mangta. Sometimes these community members would come up to me and say they are not Bedey because they are not snake charmers or their women do not perform *Shinga*. From my conversations with community members, I realized snake charmers have lower social status among the Bedey sub-groups, followed by the groups whose women perform *Shinga*, such as the Mal Bedey. On the other hand, in my interviews with Mal Bedey community leaders, when I asked who Bedey are, they considered Shandar as part of their Mangta community. From literature reviews, I knew there were multiple sub-groups within the broader Bedey community, which included Shandar.

Not everyone feels strongly about the words “*jajabor*” or “*Bedey*.” When I asked a young mother if she was offended by these terms, she explained that the name of the area where she lived her whole life is known as a Bedey neighborhood, and even *grihosthos* (Bengali) who live in this area often are mistakenly called Bedey. Since the neighborhood’s name has been there for generations, she thinks, there is no point in fighting with the older people who still call it by its old name instead of the new one. In two of the settlements, I heard their neighborhood names have been changed in an attempt to remove ‘Bedey’ from the names. In another settlement a wife of a *Sardar* told me that she still considers themselves *jajabor*, since not everyone in her

community is yet settled and many still go to *gram*—which means they go to various places, just as their ancestors did, to earn living from their traditional occupations.

From my conversations with Bedey parents and community leaders, I found their desire for social integration to be one of the biggest motivations for settling down on land. Often parents told me they wanted their children to have access to education, unlike they themselves who could not be part of formal education system due to their mobile life. Often, they hoped that education would provide an opportunity for their children to have jobs, earn money, and be respectful like others in the broader society. Comfort in life was another contributing factor. A mother, who recently settled down on land and no longer worked, told me how she enjoys the comfort in living in a house with access to electricity, television, and cooking stoves that have gas. In addition, Bedey parents mentioned how hard it is to navigate through rivers and canals now, as they are drying up. On the other hand, roads and bridges made it easy to travel far and come back the same day after work. Because they no longer feel the need to travel with boats and move around the country, parents mentioned poverty is the biggest reason why many families still live on boats.

Swapna's family, like many others, settled down on land in a group. Usually the *Sardar* makes the decision of when and where to settle down. In Swapna's case, her uncle, a *Sardar*, made the decision, helped her father to buy property together, and helped with money. There was a slow transition from their nomadic lives in a boat to a settled life on land. First, they kept their boat anchored to a river bank for years so Swapna's siblings could study in a nearby school. Her parents kept their nomadic life and went out for their traditional business for weeks and months at a time, leaving Swapna in charge of her siblings and boat. Her parents, like many others, lived in makeshift tents instead of boats, wherever they were. Years later, when her parents had some

money, the family bought land near that river bank and built a house. Three families settled down at the beginning. By the time I met her, there were about 100 families.

Bedey women's roles in the family and in the society

Swapna described a typical day of a hard-working Bedey woman. Mothers would wake up early in the morning, wash utensils, and cook for their family. They would feed their children and wash them before going to *gram*. After a long day of working outside the home, they would come back in the afternoon to cook and feed their children before sending them to bed at night. This balancing act of house chores, raising children, and earning money goes on and on in Bedey mothers' lives. They sometimes take time off when they have newborn children at home. Later, Bedey grandmothers stay at home and look after their young grandchildren when mothers go back to the field. Once the children are little older, grandmothers go back to work, leaving grandfathers and older siblings with the responsibilities of raising their siblings at a very young age while their parents work outside the home.

Swapna, being the oldest sister, was not an exception to this expectation. She took care of her four siblings, while her parents went to work. She was in charge of feeding and bathing them, and to keep an eye on them so they would not go far from the boat or fall in the water. She started to take care of them before she could even swim properly herself. Her responsibilities as an older sister of two brothers and two sisters continued for many years, and eventually, unlike her other siblings, Swapna missed her opportunity to go to a school. Similar to Swapna's family, many Bedey parents now leave their children with their extended family members so they can get access to education.

Swapna now regrets her lack of formal education. She says she was most interested in playing *ludu* with her friends and learning stitching with machine, but that she was never interested in learning a traditional occupation. Her mother also encouraged her by giving money

to get training and buying a sewing machine; eventually, Swapna became a tailor. Still, not being able to read and write is a challenge for her when she gets an order. While she has been doing this work for several years now and can estimate measurements well, she still regrets her lack of education and says to me, “[W]hat a mistake [I] made in life. Father, mother did not send [me] to school. [I] didn’t study myself. It was my own fault.”

Traditionally, Bedey mothers are the breadwinners and are engaged in traditional occupations that require them to be away from home for long hours, sometimes even days, weeks or months at a time. Where they would go and for how long they would stay there often is dictated by their *Sardar*. Moreover, Bedey women go to *gram* in groups. They spend whole days walking around looking for customers. A couple of the mothers shared with me how tiring this gets when it is hot and when they are pregnant. Many Bedey women are now leaving their traditional occupations, while more men are becoming in charge of earning money for their families. During multiple interviews, Bedey women identified their traditional occupations as one of the reasons why they are stigmatized by others. In a Muslim-dominated society, they feel it is not socially acceptable that they freely move around without *purdah* and offer traditional treatments to men. They shared with me stories of how village men and women taunt them, saying why they do not change their way of livings. I asked a few Bedey mothers how would others recognize them as Bedey? They told me that they get recognized by the way they dress, from their jewelry, language, or boats. Some mothers told me they maintain such distinctive look when they go out for work so people can recognize them and ask for their services.

Life on a boat vs. life on land

When Swapna was only about one and half years old, she fell into the water. She would not be sitting in front of me today, if she hadn’t been fortunate to have an aunt who noticed her falling and dove into the water to save her life. Swapna reminisced about her own experience

when her younger brother fell into the water while he was under her watch in her parents' absence. Swapna tells the story in great detail. She was only about 12 or 13 years old at that time and was not a strong swimmer. Her brother was then about one and half years old. One afternoon, Swapna got busy chatting with her friend while two of her siblings were napping. She did not notice when her brother woke up and fell through the boat's window. Swapna's friend heard a noise of something falling in the water and asked Swapna to check if his brother was inside the boat. Swapna did not trust her, and started to argue that it wasn't her brother, it was something else. When she finally checked, she only saw her sister sleeping and that her brother was missing. She then dove into the water to search for him, although she was not a good swimmer, and found him struggling in the water. But she could not stay long and got back to the surface. Her aunt heard the commotion and asked for help from Swapna's uncle. Initially, her uncle couldn't see the drowning child. Finally, when he saw him, he pulled the child by his legs. Swapna's brother survived, though he fell a couple of more times into the water later in his life. Unlike Swapna or her brother, many Bedey children drown. I interviewed a Shandar mother in a separate settlement who lost her child to drowning. She then decided to settle down on land.

Initially, Swapna felt lonely and missed her life on the boat with her extended family members. She used to hang out with 20-30 girls from her fleet, and now she was here only with hers and two other families. She felt sad to leave them. Eventually, "[O]ne day [life on land] felt good." Swapna referred her childhood in boats as a "dream," but confessed that she preferred the current life in a house over her life in a boat. She enjoys that she now has trees on her backyard from where she gets fresh fruits. If it pleases her, she eats them, or she sells them in the market. She lives in a two-room house on her father's land. She plans to save money and build a home of her own in her in-law's area within the next five years. Some of her family members now have

shops and sell various items, like batteries and stones. Swapna's husband manages a tea stall and she sometimes help him when she gets time after finishing her house chores and works as a tailor. Her brothers and sisters got an education and none of them are engaged in their traditional occupation, they work in the private sector. Land ownership is thus providing the Bedey community the opportunity to move beyond their traditional occupation and to own assets. As one *Sardar* told me, "[T]here was no value in the previous life," as they now have money, gold, land, and other assets.

Relationships with non-Bedey Bangladeshis

Swapna belongs to a sub-group who are known as *Mirshikari*, but they too belong to the broader Bedey group, and call themselves Mangta. Swapna's husband is a *grihostho* (Bengali), and she is not the only one who is married outside. Her maternal grandfather and paternal grandmother are *grihosthos*, like her husband. In their family, they married Bengali but not members of other Bedey sub-groups who also consider themselves Mangta, like the *Mal* Bedey. When her in-laws asked for her hand, Swapna's family felt compelled to disclose their heritage. I felt an "us vs. them" dynamic in every settlement I visited.

Due to a lack of proper address, I had to find these Bedey settlements by asking people on my way. I was surprised by how often people could show me ways to reach to a settlement from 10-15 kilometers away. Depending on the road conditions, it took me about an hour to travel by a car this 10-15 kilometers distance. Yet, almost everyone in the Bengali community knew where Bedey lived. In the majority of these settlements, social isolation was evident. I noticed surprises and discomfort in their Bengali neighbors' eyes when I walked passed their houses to enter Bedey settlements. I did not interview Bengali parents for this research, but I got to meet them and talk to them during surveys and household mapping. I rarely saw anyone going to the Bedey house, or any Bedey coming to theirs while I was in the field. I saw mosques inside

multiple settlements, but could not recall if I ever saw any of their non-Bedey neighbors entering into the mosque to pray with them. I asked a Bedey father whether any of their Bengali neighbors pray at their mosque, and he informed me their neighbors used to come to the mosque but after a dispute over land ownership, they no longer came. Land ownership is one of the major sources of tensions between Bedey and their non-Bedey neighbors. A *Sardar* shared his story how villagers came to attack them as they did not want Bedey to settle down on land beside them. Although he mentioned that relationships have improved since then, a few parents said the tension still exists. In a different settlement while I was checking household eligibility in the comparison group, I heard comments from a Bengali father that they might have to leave their home because it's getting challenging to live beside Bedey. Another grandmother in the same area shared her disapproval of the way Bedey women dressed and talk freely with their male family members in the yard.

On the other hand, in many instances Bedey community members, particularly older women, came up to me and said, “[W]e are Muslims like you” or “[W]e are Bangladeshi.” Yet, often in the interviews or in the discussions with me, they kept on referring to me as a *grehestho* and them as a Bedey. They often used “we” and “you” as in plural when answering questions saying “we do this” but “you [me and other Bengali people] do that.” In multiple interviews, their community leaders expressed that they would like to get support from the government to have better access to land, and education; however, they do not want to get recognition as a “tribe” like other ethnic minorities in Bangladesh. As their leaders told me, they want to be equal to the *grihosthos*, not like the tribal groups.

Voting rights and their sense of citizenship

In 2008, Bedey were officially granted voting rights by the Bangladesh government. Before 2008, those who had an address on land could vote, but not those who lived in boats or in tents without permanent addresses. Since then, Bedey take their voting rights very seriously. They consider having voting rights is the equivalent of having citizenship. I conducted the field study during a parliamentary election year. I could see the enthusiasm among the Bedey. Leaders gave orders to all their followers to come back to the settlements five days before the election day. A community leader said the reason he made voting so important is because “without vote our names were in the *jajabor* [nomad] list. Now [our] names are not on that *jajabor* [nomad] list. Got voting list, [became] citizen of Bangladesh.” Now they feel they have a responsibility to reciprocate by exercising their rights to vote, and to help a “good man” to win. Often their *Sardars* tell them who to vote, and they vote as a group. Their collective voices may not matter as much in the national parliamentary elections, but it does matter at the local-level elections. A *Sardar* told me: “[T]he unity that we have, it is very little in you *grigostho* people.” He then told me that if he asked the 200-300 voters in his area to “throw the votes in the river” that they would do so, and that “no one will go against” his words.

Because of their unity in supporting whoever their *Sardar* asks them to support, local politicians often try to keep them in their hands. I experienced that while I was in a settlement. In the middle of an interview, the phone rang and *Sardar* talked to a local political leader who was soliciting votes. While it is encouraging that Bedey feel connected to voting, they vote with an expectation that they will get something in return. Sometimes promises made by the elected officials are kept, and they receive tube wells, aid and allowances that come from the government. Some other times, promises are broken, or even puts them in an unfavorable situation where it creates tension between local political leaders and them. However, they feel

proud of their voting rights, and feel it's their "responsibility towards the country" to vote. Mobile Bedey parents leave their boats and tents behind, miss work, and come back to the settlement a few days early when their *Sardar* asks them to come. Those who do not have a place to stay, *Sardar* arranges their lodging and food for these days. They even teach each other how to fold the ballot paper so their votes are counted.

Chapter IV: Study Implications

Discussion

This study found that current approaches to childhood vaccinations are falling short in efforts to reach the mobile and culturally unique populations in Bangladesh. This is evident by the high number of unvaccinated children found in Bedey community compared to the comparison group. Of the 101 unreached children—who never received any vaccines—96 are Bedey, and only 5 are Bengali children. It was also found that the odds of having unreached children in the Bedey community were much higher compared to the comparison group after being adjusted for parent, household and child-specific characteristics (OR=10.64, 95% CI: 3.49-32.44, p-value < 0.0001). Qualitative data uncovered a lack of guidelines in categorizing a child as "outsider" vs. "local," requirements for a child to stay for an extended period in an area to avoid being listed as a dropout in EPI record, misinformation or lack of information about vaccines and their benefits, and a failure to recognize that Bedey function as a group and that their social isolation is contributing to low immunization coverage.

The current vaccine delivery model has a geography-based approach that was constructed on an assumption that populations are not mobile, and children who are considered "outsider" in one place would be residing somewhere else permanently, and therefore will be part of a different community's target population. This region-based approach limits service providers' responsibilities, and makes them accountable only for those who are residing for a significant

time within this catchment area. A program's success and vaccinator's performance measurements also have a geographic boundary, since goals are set and measured by the proportion of target population who received vaccines within a catchment area. On the other hand, high numbers of unreached children or dropouts indicates poor program performance; and vaccinators and their supervisors are held accountable in the hierarchical reporting and managerial structure at the EPI and in the government health care sector. This creates a system where it incentivizes vaccinators to keep mobile children—who are at high risk for being considered dropouts—in the “outsider” list. They are thus not considered a part of the target population in their catchment areas, and therefore, service providers are not held accountable for these children in the measurement of the program's success. Moreover, in the absence of a proper guideline on determining a child “local” vs. “non-local,” determination is often subjective and is mostly dependent on the vaccinator's judgement. From the service provider interviews, it was found that mobile children are sometimes left off the “local” children's list in the EPI register because health assistants fear “register books will be empty” if they include them. Sometimes this happens to mobile children in the areas where their parents are registered voters, and are considered “local” in the national census. Thus, many mobile children, such as the Bedey children, are falling through the cracks and are not included in the target populations anywhere in the country.

This lack of inclusion in the denominator contradicts the Decade of Vaccines' vision of universal access to immunization and gives a false narration of program success and equity. In a study involving Roma children between the ages of 6–59 months in Belgrade, Serbia, full and timely-vaccination coverages were found extremely low—only 16% for OPV and DTP, and 14% for MMR.³³ This study included Roma children from both legal and illegal settlements, and birth

registration was found to be a predictor for vaccination and possession of immunization cards. Describing the probable explanations for finding such low immunization coverages compared to the previously reported ones, the authors commented on the Serbian Ministry of Health's practices of considering children who are registered as citizens as the denominator in calculating vaccination coverages. Consequently, the authors indicated many of the children who participated in the study were not "visible" to the State and had limited, if any, access to its services,"³³ since only registered citizens with health insurance cards can access primary health care centers' services. Although mobile Bedey children are not required to have their birth certificates in order to receive vaccines from vaccine centers, their lack of inclusion in the "local" children's list, therefore in the denominator, make them invisible to the Government's eyes.

An "outsider" status does not preclude a child from getting vaccines from a center as long as they carry a vaccine card and the center has the vaccines in stock. However, this places the entire responsibility on the mobile parents' shoulders, and not on the service providers. Vaccinators are expected to spend a day in the field in each of the EPI sub-blocks to motivate parents and reminding them to bring their children in the following outreach session as part of the Inter-personal Communication (IPC) initiative. This reminder system works only if the children are known to the vaccinators or their names are on the list. Otherwise, parents are expected to be proactive, and to bring their children to the vaccine centers on their own. This means parents need to know when and where to go to get the vaccines. Since mobile children's names are often not on the "local" children's lists anywhere, their parents are expected to take the initiatives and to bring them for vaccinations. Moreover, mobile parents are expected to carry vaccine cards with them all the time, and to actively search for nearby vaccine centers in

multiple locations along their ways until their children complete vaccinations. These are unrealistic expectations of any mobile parents, let alone of the Bedey parents for the reasons soon to be discussed.

High mobility is often identified as a challenge in accessing vaccination programs by both Bedey and the service providers who participated in the interviews. However, a Chi-square test showed no statistically significant difference in number of unreached children between settled and nomadic Bedey households in both rural ($p\text{-value}=0.90$), and urban areas ($p\text{-value}=0.42$). Families living in tents and boats were considered as nomadic Bedey for the purpose of this study since they are the ones who often move around the country, compared to those who now live in stable housing on land. This lack of statistically significant difference indicates high mobility is only part of the problem. Moreover, neither children's age nor place of residence were found to have statistically significant association with the number of unreached children in both univariable and multivariable logistic regressions (Table 7). This suggests vaccination coverages in Bedey community have not improved over the past 10 years in either rural or urban areas, despite the recognition of their voting rights in 2008 and increases in numbers of settled families since then.

Multiple sociocultural factors were identified through the field observations and participant interviews that are contributing to this low vaccination coverages among both settled and mobile Bedey families. Our survey data shows that the majority of the Bedey mothers (97% rural and 61% urban) and Bedey fathers (67% rural and 49% urban) never had formal education (Table 2). This low literacy makes it difficult if not completely impossible for the Bedey parents to follow the complicated chart on the vaccine cards that shows the return dates. In addition, from the field observations and interviews it was found that Bedey community still follows

Bengali calendar to record major events. Often, they mentioned Bengali months in which their children were born or they were away from home to earn livings. On the other hand, the outreach sessions run once every four weeks and follows an English calendar, which may add additional confusions for the Bedey parents who have low literacy. This is a particularly important obstacle for mobile parents who are left with the responsibilities to actively search for nearby vaccine centers on specific days of the month that varies from one place to the other. The importance of mothers' education was supported by both univariable (OR = 0.06, 95% CI: 0.03-0.12, p-value < 0.0001) and multivariable (OR =0.29, 95% CI: 0.13-0.64, p-value=0.002) logistic regression, where it was found odds of having unreached children is lower among mothers who had formal education (Table 7). This aligns with findings from other studies where a mother's education was found positively associated with high immunization coverage.^{2,3}

Moreover, traditionally Bedey mothers are the breadwinners who are engaged in their traditional occupations that require them to be away from home for long hours, sometimes even days, weeks, or months at a time. In the study sample it was found that almost half of the Bedey mothers were engaged in income-generating activities at the time of the survey compared to less than one-tenth of the Bengali mothers (Table 2). After being adjusted for parent, household, and child specific characteristics, mother's employment (OR =2.19, 95% CI: 1.11-4.33, p-value=0.024) was found to be a risk factor for unreached children (Table 7). This is counterintuitive since a mothers' engagement in income-generating activities was found to be positively associated with timely vaccination of children in Gaibandha and Rangpur districts of Bangladesh.² From the qualitative data and field observations it was evident that Bedey mothers are expected to be in charge of house chores, raising children, and earning money. Sometimes they get support from their husbands, older children, or from extended family members.

However, for the most part, responsibilities for raising children fall on them. Qualitative findings show how Bedey mothers often fail to understand preventive intervention's benefits due to its non-emergency nature. They find it particularly challenging to balance house chores and work outside home when their children are sick at home suffering from vaccine's side effects. They fear losing money by missing work or spending money on medications to manage vaccine's side-effects. Thus, when it comes to prioritizing their duties, it may not be a priority for Bedey mothers, particularly the ones who still have nomadic lives, to carry vaccine cards with them all the time and to actively search for nearby vaccine centers.

This lack of priority partly explains the existing knowledge-action gaps that were found in the Bedey community (Table 6). Although in both rural and urban areas, Bedey parents are found to be less knowledgeable compared to their respective comparison groups, the majority of the Bedey who took part in the survey considered vaccines to be good for their children and knew locations of the nearby vaccine centers, most of which were identified as reachable within 30 minutes on foot by the Bedey parents (Table 6). Field observations of Bedey settlements, and the nearby vaccine centers confirmed their geographical accessibility. Yet, the number of unreached children among rural (62%) and urban Bedey (42%) was high. This indicates that a proportion of Bedey parents who think vaccines are good for children, and knew where to go to get vaccines did not vaccinate their own children. Similar high awareness, yet, low vaccination coverages were found among migrant Santal children in urban slums of Orissa, India. 90% of the Santal mothers were knowledgeable about various essential vaccines, yet 25% of the children never received any vaccines.³⁴

In addition to competing priorities that Bedey mothers have in their daily lives, not knowing when vaccinators come to the outreach centers was identified as a key challenge by the

Bedey mothers that also partly explains this knowledge-action gaps. Therefore, the expectations of mobile parents to actively search for nearby vaccine centers and to reach there on specific dates when vaccines are available are not realistic expectations. Moreover, Bedey parents are members of the broader Bedey community. Field observations and in-depth interviews support what was found in the literature reviews. Bedey still maintained their traditional social structure where they live, travel and work as a group surrounded by their extended family members and other Bedey community members. They strictly follow *Sardar*'s decisions and guidance in almost every aspects of their lives that include: where and when to settle down, where to go to earn livings, which month of the year to return to the settlements, and whom to vote for, among others. They often get influenced by each other's opinions and make decisions collectively. Rumors travel fast in Bedey communities. Rumors of children dying from vaccines were mentioned by several Bedey parents from different Bedey sub-groups in multiple study locations. This rumor played a significant role in undermining their trust in vaccines as they got fearful and collectively refused to vaccinate their own children. The power of rumors in rejecting vaccines by marginalized communities that have social disadvantages, such as poverty and low literacy, were seen in India and Nigeria. In both cases communities perceived threats from the outsiders as the rumors were "polio vaccine was a Western ploy to sterilize Muslims."³⁵ From the interviews it was found that Bedey parents' distrust came from their lack of trust in government facilities, as their fear was children—whom they heard died after vaccinations—were given expired vaccines.

In addition to the influences of the broader Bedey community, it was also found that individual Bedey mothers' vaccine-related choices are sometimes limited by their husbands or in some cases, by their in-laws. Although a small number of Bedey parents from the surveys

acknowledged involvements of their extended family members in the vaccine-related decisions, qualitative interviews revealed extended family members, particularly, mothers-in-law often play important roles. The study found that influences of mothers-in-law can act either as a support or as an obstacle depending on their own trusts in vaccines. Thus, the current public health messaging and the Inter-personal Communication (IPC), which target mainly individual mothers, is proven to be insufficient for Bedey community.

Another key factor that affects Bedey's access to vaccination programs is their social isolation. This study found that "geographical accessibility" does not guarantee "social accessibility" to vaccine centers. Despite of Bedey community members' interests and willingness to cooperate, almost all the outreach sessions in the study area are operated in non-Bedey households or in schools. Health assistants' perceptions of Bedey settlements being unsafe and not suitable to have outreach centers actively exclude Bedey households from having EPI outreach centers. This affects Bedey children's access to vaccination programs due to lack of social integration and often contentious relationships with their non-Bedey neighbors. Sometimes Bedey feel they are being left out intentionally, particularly in settlements where they have contentious relationships with their neighbors. They feel unwelcomed and suspect their neighbors warn the vaccinators not to go inside their settlements. On the other hand, non-contentious relationships with the broader society often provide opportunities to Bedey parents to learn about vaccines' benefits, and key information about when and where to go through their interactions with Bengali population at various social settings as was evident from some interviews.

Of the 147 vaccine cards that were found during surveys, 51 belonged to Bedey children. Vaccine data collected from vaccine cards showed a large proportion of these 51 Bedey children

received vaccines that they were eligible to receive at the time of the surveys (Table 5). This indicates dropouts in Bedey community could be less big of a problem once they become part of the vaccine program compared to the number of unreached children who remain outside of it for various reasons discussed above. From the service providers' interviews, three major avenues were identified by which vaccinators become aware of new eligible children in their catchment areas. First, when a pregnant mother receives tetanus vaccines her name gets into the EPI register and vaccinators then follow-up with them once they have children. Second, vaccinators are often from the same area where they work, and therefore they are socially well-connected and receive information about pregnant women through their connections with the community. Third, proactive mothers bring their children to the vaccine centers the first time, and once their names are on the roaster it falls on the vaccinators to follow-up with them as long as they stay in their catchment areas. Field observations of the settlements found that when settlements are large, or are not visible from the main roads, and when Bedey families exclusively live among themselves in clusters, vaccinators are less informed about the number of eligible children residing inside these settlements, either permanently or temporarily. Moreover, none of the service providers in the study areas are Bedey, therefore, they are socially less connected to the Bedey community, and are less informed.

Limitations of the study

The study had several limitations. First, simple random selection of Bedey settlements or households was not possible in the absence of a reference frame since there is no official record of the total number of Bedey in Bangladesh and the locations where they live. Hence, the study findings should be interpreted with caution before generalizing them to all Bedey communities across Bangladesh. To improve external validity, efforts were made to include settlements from different geographic locations with diverse contextual characteristics. Data were collected from

15 locations across 10 districts in Dhaka and Barisal division. Efforts were made to include Bedey settlements that are more permanent in nature, as well as the ones where many families still have nomadic life. At least five different sub-groups of Bedey (*Mal, Shandar, Laoa, Mirshikari*, and Snake charmer) participated in the study.

To improve generalizability in the sampling, data were collected from six randomly selected settlements—of the fifteen in total under study—from a list compiled with the help of Bedey community leaders and an NGO that has worked with them in the past. Initially, 11 settlements were randomly chosen from this list; however, 5 of these randomly selected settlements could not be included for reasons, such as, a slum got destroyed and families had to move away, temporary settlements moved to new locations, etc. Therefore, 9 settlements were purposively chosen, based on their potential nomadic life and other contextual characteristics. In addition, randomization was included at the household-level. Efforts were given to map entire settlements, where it was feasible, or to map a randomly selected segment of large settlements to prepare a list of Bedey households and to screen for their eligibility. Households were then randomly selected from this list, and data were collected for eligible children.

Since very little was known about Bedey community's access to vaccination programs, and overall, access to health care, children aged between 0 to 10 years were included in the study that gave the opportunity to assess whether accessibility to vaccination programs among Bedey changed over the past 10 years since official recognition of their voting rights in 2008 and therefore, citizenships. This increased the likelihood of introducing information bias, particularly for children whose vaccine cards were not available at the time of the study, requiring researchers to rely on parent's memory. This is a threat to internal validity. A large number of the households were expected not to have vaccine cards due to various factors such as low

literacy and the migratory nature of the Bedey community. Efforts were given to minimize information biases regarding individual vaccines and its doses. Survey questionnaires were adapted based on the findings and experiences of the pilot study. Survey questions included names of the diseases in the local terms so parents understand which vaccines and diseases surveyors were referring to, visual aids showing children receiving vaccines, and locations where children are expected to receive injections for a particular vaccine were also used. From the experiences of the pilot study, it was expected that some of the children would be receiving vaccines from multiple locations. Therefore, questions were asked how many times children received injections and from where, in order to stimulate recollection rather than asking when these injections were given.

Moreover, in the qualitative interviews some Bedey parents, who were often purposively selected from the survey responses, indicated that when vaccinators approach them, they are able to send them away by falsely reporting that their children have already been vaccinated so they are not judged or bothered by them. This was corroborated by a service provider's interview, when she shared her experience where families told her that their children received vaccines when she suspected they did not. Therefore, in the Bedey group vaccination coverage could actually be lower than the estimation due to social desirability bias. However, these biases are not likely to change the primary conclusion of the study that the number of unreached children is much higher in Bedey community compared to the comparison group for the following reasons:

- First, of the 369 children, vaccine status was verified for 147 children from their vaccine cards.
- Second, at the beginning of the vaccine related questions in the survey, parents were asked separately whether their children ever received any vaccines orally, and whether

their children ever received any vaccines in the form of injections. This was done because the pilot study found that some parents do not consider oral polio drops as vaccines, and they only consider injectable ones as vaccines. Parents of 101 children, 96 of whom are Bedey children, said they never had any injections, and none but one had a vaccine card. (The child who was the exception was given a card after registration but never received vaccines as he was sick at that time.) These data are much less prone to recall bias than asking for specific vaccines and their subsequent doses. This is supported by the qualitative interviews, in which some Bedey parents (who were often purposively selected from their survey responses) shared their fear of injections and mentioned how it was a challenge for them to overcome this fear to provide vaccines to their children. Few mothers even mentioned fear of injections were one of the reasons why they decided not to give vaccines. Some others mentioned their fear of vaccines' side effects, including having sores at the injection sites, and rumors of children dying from vaccines as reasons for not vaccinating their children. Therefore, parents' memories about whether their children ever received any injectable vaccines is expected to be reliable for this particular study population.

- Third, BCG scars were checked in children when they were available at the time of the surveys. Of the remaining 122 children, a BCG scar was found in 92 which confirmed these children had at least one dose of BCG vaccine, and therefore, cannot be identified as unreached children.

In addition to the reasons discussed in the discussion section, the knowledge-action gaps among Bedey community could also partly be explained by social desirability bias. Many parents might have shared what they hear from others and public health campaigns about vaccines,

without reflecting their own trust in them. For an example, Bedey's involvement with traditional medicine may have some influence on their trust in modern medicine and therefore vaccines. However, very few parents mentioned about going to traditional healers for treatments. Social desirability bias might have prohibited participants from sharing their thoughts and opinions regarding vaccines.

Furthermore, it was found that some Bedey families have permanent housing in the settlements, yet they have nomadic life and live in tents for weeks and months at a time away from their home. On the other hand, while some families live in boats and move around, some others stay at a location for long time. Nomadic vs. non-nomadic classification was done based on where the families were living at the time of the interview for this study. Lack of clear distinction between nomadic vs. non-nomadic settlements or households might explain the comparability of unreachable children between the two Bedey groups.

Strengths of the study

There are several strengths of this study. Data were collected from 15 locations across 10 districts in Dhaka and Barisal division that made it possible to include different geographic locations with diverse contextual characteristics, such as urban and rural residence, nomadic and non-nomadic Bedey settlements, high and low vaccine coverage districts, etc. In addition, data for the comparison group were collected from the same ward, and often from the same EPI sub-block as of the Bedey settlements. This reduced geographical variability, and some contextual variability between Bedey and non-Bedey participants. Moreover, at least five different sub-groups of Bedey (*Mal, Shandar, Laoa, Mirshikari*, and Snake charmer) participated in the study. A pilot study at the beginning made it possible to clarify and adapt the data collection tools making them more suitable for the local context.

Due to the study's convergent mixed-methods design, quantitative and qualitative data were collected and analyzed simultaneously, yet, separately. Findings were only integrated at the final results stage, and concordance and divergence in the interpretation and implications of the findings were evaluated. Moreover, surveys helped to identify interviewees with potentials to provide comprehensive views on the research question representing views of both nomadic and non-nomadic Bedey parents from urban and rural areas of vaccinated and unvaccinated children. Furthermore, field observations and in-depth information on the lived-experience of being Bedey helped to explain how being Bedey affect their access to formal medical services, including vaccinations. Service providers from both high and low vaccine coverage areas were included in the study to gather comprehensive perspectives on vaccine delivery challenges and successes among Bedey children.

Most importantly, the mixed-methods study design made it possible to go beyond establishing “point estimates” resulting from a cross-sectional survey which was not sufficient to inform policy about why vaccine coverage gaps exist, and how to bridge the gaps. The qualitative results, and field observations helped us to dig more deeply to understand and explain the mechanisms by which the existing vaccination programs are failing to reach communities that are mobile, or have unique socioeconomic, political, cultural and historical background, such as the Bedey.

Implications of the study and next steps

In conclusion, current approaches to childhood vaccinations are falling short of their efforts to reach mobile and culturally unique populations in Bangladesh. This is evident by the high number of unreached children found in Bedey community compared to the comparison group. It was found that the odds of having unreached children in Bedey community were much higher compared to the comparison group after being adjusted for parent, household and child-

specific characteristics (OR=10.64, 95% CI: 3.49-32.44, p-value < 0.0001). Moreover, the entire vaccine delivery model has a geography-based approach where areas are defined as “hard-to-reach” when they are geographically difficult to reach, such as the char, haor, enclaves and hilly areas, and most importantly, if it requires more than 2 hours to reach to the distribution point from the Upazilla Health Complex, or from the distribution point to the vaccination sites.⁷ As shown in this study, all the Bedey settlements, and nearby vaccine centers are geographically accessible, and therefore, are not considered as “hard-to-reach” by the service providers. On the other hand, mobile population and slum dwellers are considered as high risk populations in the EPI Management and Microplan Guide, among others.⁷ Therefore, by this definition, Bedey community should be considered as a high risk population. However, from conversations with service providers at the sub-district and national-level, as well as review of policy documents, it was evident that some special considerations and efforts are given for geographically hard-to-reach areas, while very limited attention has been given to high risk populations.

Furthermore, the geography-based approaches to service delivery have an assumption that if area-wise targets are fulfilled, that will include everyone, regardless their ethnicity or other sociocultural factors. Findings of this study show that this assumption is not valid as high mobility and social isolation sometimes exclude Bedey children from the target population, even where they were born and their parents are registered voters. Based on the study findings it is evident that while some socioeconomic risk factors—high mobility, low literacy, and poverty—are common between Bedey and other vulnerable communities, such as the urban slum dwellers; some other characteristics and circumstances are unique to Bedey, particularly their group dynamic and social isolation that demands targeted interventions for them. Based on the study

findings, and considering Bedey's unique sociopolitical, cultural, and historical contexts the following are recommended to improve access to vaccination programs among Bedey children:

- First, public health messaging and outreach efforts should be targeted to Bedey communities as a whole. In addition to engaging Bedey mothers during IPC, Bedey community leaders and Bedey fathers need to be engaged in the communications. Bedey community leaders can act as a liaison between Bedey parents and service providers. They will be particularly useful in giving information regarding pregnant women and newborns in their community. Moreover, they are often knowledgeable about the whereabouts of the nomadic Bedey families, including their estimated return dates. In studies outside of Bangladesh, participation of nomadic community leaders has proven to be useful, especially when combined with other strategies, such as sending mobile vaccine teams, in improving vaccination coverages among nomadic children (for example, in Chad³⁶).
- Second, awareness should be created among traditional birth attendants, elderly Bedey women and men, and neighborhood pharmacies and village doctors as part of the IPC who deliver care to Bedey mothers and their children. Facility-based delivery is very low among Bedey. Moreover, Bedey often seek care at the unregulated pharmacies near their homes. Therefore, children often do not encounter trained professionals unless they are critically ill. Individuals involved in delivering care to Bedey parents and their children need to be identified and included as part of the community engagements.
- Third, cell phones should be used for reminding and tracking Bedey parents. 95-100% of the Bedey households had access to cell phones in the study area. This communication device should be utilized, and vaccinators should be using cell phones as part of the IPC

to remind parents to bring their children in the sessions. This would also allow vaccinators to remind parents who are away from the settlements. This way mobile Bedey parents will be knowledgeable about when to go to a nearby outreach session. Use of cell phones has already been shown to improve vaccination coverage among rural hard-to-reach and urban street dwellers in Bangladesh³⁷. In this study text messaging was used as a reminder. Since most Bedey parents never had formal education, voice calls could be an option for them.

- Fourth, outreach centers should be located in Bedey households, particularly in the large settlements where it is harder to track children by the vaccinators. This will provide the “social accessibility” that is currently missing.
- Lastly, and most importantly, requirements for children to stay long at a place to be consider as “local” should be eliminated. Regardless a family’s high mobility, children should be considered “local” and vaccinators should be in charge of following up with all children in his area.

In the absence of data specific to ethnic minorities and other vulnerable communities, knowledge is limited as to what factors contribute to access-barriers among geographically accessible, yet, culturally unique populations. Further studies should be conducted to assess vaccination coverages among other ethnic-minorities (such as Chakma, Marma, Garo, etc.) in Bangladesh. In addition, future investigations can explore whether any of the specific sub-groups within the larger Bedey community are more at risks for low vaccination coverage than the rest. Although this study did not look at the coverage differences between different Bedey sub-groups, general impressions from the field observations and data is that vaccination coverages among Mal Bedey could be much lower compared to the others, particularly Shandar group. Moreover,

a culture-sensitive community health worker-based model could be explored to reach Bedey children.

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