Estimating stillbirth and neonatal mortality rate among Rohingya refugees in Bangladesh, September 2017 to December 2018: a prospective surveillance

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ABSTRACT

Introduction There is limited literature on neonatal mortality in humanitarian emergencies. We estimated neonatal mortality and stillbirth rates; determined whether an association exists between proximity to a secondary health facility and neonatal mortality or stillbirth; and tested the correlation between the number of health facilities in a camp and neonatal mortality or stillbirth rates in Rohingya refugee camps in Bangladesh.

Methods We conducted a prospective community-based mortality surveillance in 29 out of 34 Rohingya refugee camps between September 2017 and December 2018, covering approximately 811,543 Rohingya refugees with 19,477 estimated live births. We linked mortality surveillance data with publicly available information on camp population, number of functional health facilities and camp and health facility geospatial coordinates. Using descriptive statistics and spatial analyses, we estimated the mortality rate and tested for correlations.

Results Overall, the estimated neonatal mortality rate was 27.0 (95% CI: 22.3 to 31.8) per 1000 live births, and the stillbirth rate was 15.2 (95% CI: 10.8 to 19.6) per 1000 total births. The majority of neonatal deaths (76.3%, n=405/531) and stillbirths (72.1%, n=202/280) occurred at home or in the community. A positive correlation existed between the camp population size and number of health facilities inside the camp (Spearman’s rho=0.56, p value<0.01). No statistically significant correlation existed between the camp neonatal mortality rate or stillbirth rate and number of health facilities inside the camp. Camps that were located closer to a secondary health facility as compared with a labour room/sexual and reproductive health unit had a lower neonatal mortality rate and a lower stillbirth rate.

Conclusions The results provide insight into the neonatal mortality and stillbirth rates in Rohingya refugee camps in Bangladesh during 2017–2018. Prospective community-based mortality surveillance may be a feasible method to evaluate the effectiveness of humanitarian responses in improving neonatal survival and preventing stillbirths.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ The acute phase of a humanitarian crisis, defined as the first 6 months after an event, often increases the risk of under-five mortality.

WHAT THIS STUDY ADDS

⇒ Rohingya refugees in Bangladesh had substantial neonatal mortality and stillbirth rates between September 2017 and December 2018.
⇒ The majority of the neonatal deaths and stillbirths occurred at home or in the community.
⇒ No significant correlation between number of health facilities in camp and neonatal mortality or stillbirth rates of camps.
⇒ Camps that were nearer to secondary health facility as compared with labour room/sexual and reproductive health unit had a lower neonatal mortality rate and a lower stillbirth rate.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE AND/OR POLICY

⇒ Humanitarian responses need to increase the availability and utilisation of health services and quality of care during pregnancy, childbirth and the immediate postnatal period.

INTRODUCTION

The armed conflict in Rakhine state of Myanmar instigated the displacement of an estimated 882,000 Rohingya people from Myanmar to Cox’s Bazar district of Bangladesh in 2017 and 2018. The majority (707,000, 80.0%) of these refugees, referred to as Forcibly Displaced Myanmar Nationals by the Bangladesh government, arrived in Bangladesh in the last quarter of 2017. Most of the refugees settled in Ukhiya and Teknaf Upazilas in Cox’s Bazar district, where pre-existing Rohingya refugees had already settled.

In response to this humanitarian crisis, the government of Bangladesh, United Nations
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tarian crises.15 16 This is due, in large part, to complex
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 communities gain access to food, shelter, water, sanita-
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The acute phase of a humanitarian crisis, defined as
the first 6 months after an event, often increases the risk
of under-five mortality.3, 5 6 This increase in under-five mortality is due primarily to the increase in incidence of communicable diseases, such as measles, pneumonia, diarrhoea and other neonatal causes.5 6 Over the last two to three decades, the importance of the neonatal period, 0–28 days of life, has come into focus.6 7 Globally, neonatal mortality accounts for nearly 47.0% of under-five mortality.7 Typically, the initial increase in under-five mortality starts to decline once conflict-associated insecurity improves, vaccination campaigns are conducted and communities gain access to food, shelter, water, sanitation, nutrition and healthcare services.5 However, the evolution of neonatal mortality through the phases of a humanitarian emergency is unknown.

Few mortality studies have been done or published since the arrival of Rohingya refugees in Bangladesh in August 2017. A household survey in December 2017 by Médecins Sans Frontieres estimated under-five mortality to be 0.74 (95% CI: 0.43 to 1.27) per 10 000 children under-five per day.3 However, this survey did not produce data on stillbirth rates or neonatal mortality. The limited data available on neonatal mortality and stillbirth or coverage of services among Rohingya people is pre-crisis. The pre-crisis neonatal mortality rate, measured through a household survey of Rakhine state, Myanmar, was estimated as 32 deaths per 1000 live births in 2015–2016,9 and the national stillbirth rate was estimated as 14.1 (95% CI: 8.6 to 23.8) per 1000 live births in 2019.10 Pre-crisis data on facility-based delivery in Rakhine state was 19.2% in 2015–2016.9 Previous studies in Rohingya refugee camps have found a similarly low proportion of facility-based delivery: 3.9% in November to December 2017,11 and 22.0% in 2018.3

Indeed, the lack of data on neonatal mortality and still-
births are not unique for the Rohingya crisis. Few studies have reported neonatal mortality12-14 and even fewer studies report stillbirths in the acute phase of humani-
tarian crises.15 16 This is due, in large part, to complex
methodological challenges in the acute phase of a humani-
tarian crisis. In the absence of civil registration of vital events (ie, births, deaths), low-income and middle-
income countries depend on household surveys, such as the Demographic and Health Survey (DHS), to estimate neonatal mortality.17 18 The DHS uses full birth history and/or full pregnancy history as recalled retrospectively by the respondent that captures data from women of reproductive age on their pregnancies and pregnancy outcomes.18 The full birth history captures a woman’s lifetime live births and newborn survival status. The full pregnancy history captures miscarriages, stillbirths and live births and the newborns’ survival status. However, humanitarian mortality surveys often count deaths as recalled by the respondent (any adult in the household) retrospectively over a prespecified recall period where the respondent is asked if there were any deaths and live births in the household, thus potentially missing early neonatal deaths,19 tend to have insufficient sample sizes to accurately capture neonatal mortality because neonatal deaths are relatively rare events, and are not designed to measure stillbirths.20 21 Alternative methodologies that use health records, perinatal/neonatal rapid assessment process for institutional delivery,22 and agency-based health information systems,15 23 tend to underestimate the true magnitude of deaths, as most childbirths in humani-
tarian crises occur at home.

Community-based mortality surveillance systems with high coverage (≥90.0%), data accuracy and reporting timeliness (within a week) have the potential to provide better neonatal mortality estimates to inform public health action.20 Community-based surveillance systems could also provide an avenue for counselling, referral to care and tackle misinformation and stigma that might be associated with stillbirth and/or early neonatal mortality. To better understand the maternal mortality, stillbirth and neonatal mortality of the Rohingya refugees in Bangladesh, the US Centers for Disease Control and Prevention (CDC), in collaboration with organisations that were providing healthcare services in the Rohingya refugee camps, conducted prospective community-based mortality surveillance. This manuscript describes the findings on stillbirths and neonatal mortality rates of the Rohingya refugees in Bangladesh during September 2017 through December 2018.

METHODS

The Rohingya refugee settlement, which was considered the largest refugee camp in the world as of 2020, is subdivided and demarcated for administrative reasons into 34 camps (figure 1).2 24 A prospective community-based mortality surveillance was conducted in 29 out of 34 (85.3%) Rohingya refugee camps in Cox’s Bazar district, Bangladesh, from 1 September 2017 to 31 December 2018. The 29 camps were selected purposively based on operational presence of partner organisations. The surveillance data were linked with publicly available data

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on health facility availability, population size and geospatial information. Healthcare provision within these camps was a result of a collaborative effort of various organisations, such as non-governmental organisations, UN, Bangladesh government as described in the health sector reports.4

Prospective mortality surveillance
The prospective community-based mortality surveillance was set up by the CDC and conducted by UN agencies, the Ministry of Health and non-governmental organisations. Data collectors were trained on case definitions and data collection methods. Stillbirth was defined as fetal death at ≥28 weeks of gestation and neonatal death as death between 0 and 28 days of life, as recommended by WHO.25 The mortality surveillance captured information on residence (camp designation), family name, date of death (day/month/year), age of the newborn (in hours or days) and place of death (home, community or health facility). Stillbirths were recorded as zero hour, age and sex (female/male). Identification and reporting of mortality was conducted by community health workers (CHWs), who visited all households weekly in their catchment areas. When a death or stillbirth was reported by the family, the CHWs completed a general mortality report. If the death was a neonatal death or stillbirth, the CHWs recorded the information in a separate form and alerted their supervisor. The supervisors checked the report for completeness and accuracy and verified the information by revisiting the household, as needed. The supervisor was to then submit the report to the nearest health facility to be checked and signed by a physician. The implementing partner then uploaded the de-identified data to a platform on KoBo.26 These delinked data were then shared with the authors for analysis.

Health facility mapping
The health cluster and the Inter Sectoral Coordination Group (ISCG) regularly (every month or every 2 months in the first half of 2018 and irregularly for the latter half of 2018) conducted Rohingya situation assessments and health facility mapping reports.24 For this analysis, the May 2018 report was selected as an approximation of the midpoint for the surveillance period of September 2017 to December 2018.4 The variables extracted were the health facility name, health facility managing agency, care level (health post, primary healthcare centre, secondary health facilities, labour room/sexual and reproductive health units and specialised services), functionality (functional vs non-functional), hours of operation and geospatial coordinates.

Estimation frameworks
Changes in camp label were reconciled by reviewing various situational reports from the International Office of Migration (IOM) and the UN Agency for Refugees (UNHCR). Each camp has a population estimate from IOM2 and UNHCR1 and geospatial coordinates which were reported by the ISCG. ArcGIS maps, provided by the ISCG, were used to estimate the footpath distance from the geospatial coordinates of the camp to the specified health facility.24

To estimate stillbirth and neonatal mortality rates, the total number of live births was calculated by applying the IOM population estimate of 811,543 persons residing in the 29 camps (as of, May, 2018) the crude birth rate of 18 per 1000 persons per year as found by DHS Myanmar 2015–2016 report,9 and the study period of 16 months. We selected the IOM population estimate as the data are regularly (monthly in the first half of 2018) updated, methodology was deemed robust by the authors and population estimates per camp were available for May 2018. The UNHCR population estimate (n=796,304) confirmed the data from IOM and had similar neonatal mortality and stillbirth rate (table 1). Though other estimates of crude birth rates for Rohingya refugees are available we used the DHS estimate.9 The DHS has robust methodology to estimate crude birth rates, using pregnancy history, and is the standard in global health.16 Total births were calculated as the sum of the estimated live births described and stillbirths captured through our community-based surveillance. The neonatal mortality rate was defined as the number of newborn deaths from 0 to 28 days of life per 1000 live births. Stillbirth rate was defined as the number of stillbirths per 1000 total births.

Statistical analysis
Descriptive statistics, t-tests and linear regression were used to: characterise the population, health facility and mortality distribution; estimate neonatal mortality and stillbirth rates; and test the correlation between neonatal mortality or stillbirth rate and the population adjusted number of health facilities in the camp. The correlation between neonatal mortality or stillbirth rate and the number of health facilities was estimated using Spearman’s rho (non-parametric test). Scatter plots were used to visualise the correlation and distribution of health facilities by neonatal mortality and stillbirth. To determine an association between proximity to a specific type of health facility designated to provide neonatal and labour care and neonatal mortality or stillbirth, we split camps into two categories: (1) those that were closer to a secondary health facility versus (2) those closer to a labour room/sexual and reproductive health unit. We then used Welch t-test to compare the mean estimated neonatal mortality rate and stillbirth rates in the two categories. Statistical significance was defined as p value<0.05. All analyses were performed with Stata statistical software V.16 and R V.4.0.2 environment.27 28

Patient and public involvement statement
Patients and the public were not involved in the study design. CHWs engaged in data collection were from the refugee community. Estimated neonatal mortality and

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Patients and the public were not involved in the study design. CHWs engaged in data collection were from the refugee community. Estimated neonatal mortality and
stillbirth rates were shared with implementing partners for broader dissemination.

RESULTS
Overall, an estimated 530 neonatal deaths and 280 stillbirths were reported from 1 September 2017, to 31 December 2018, in 29 of 34 Rohingya refugee camps in Bangladesh, resulting in an estimated neonatal mortality rate of 27.0 (95% CI: 22.3 to 31.8) per 1000 live births and a stillbirth rate of 15.2 (95% CI: 10.8 to 19.6) per 1000 total births (table 1).

The lowest number of neonatal deaths was observed in camp 20 (3 neonatal deaths) and the greatest number in camp 1E (39 neonatal deaths). After adjusting for population size, the greatest neonatal mortality rate was reported in camp 6 (59.8 per 1000 live births) and the lowest in camp 12 (10.2 per 1000 live births) (figure 1).

Camp 22 had the greatest stillbirth rate (37.2 per 1000 total births) after adjusting for population size (figure 2).
The majority (76.3%, n=405/531) of neonatal deaths occurred at home or in the community, defined as deaths that occurred in transit or outside of health facilities. Similarly, 72.1% (n=202/280) of stillbirths were reported to have occurred at home or in the community (table 2).

Overall, the May 2018 data set contained 338 health facilities, 280 of which were functional, 57 facilities that were non-functional (under construction, planned or permanently closed) and 1 health facility had missing data on functionality. Of the 280 functional health facilities, 248 (88.6%) were located in the 29 Rohingya refugee camps where the prospective surveillance study was conducted. Out of the 248 health facilities located in the 29 camps, 61.3% (n=152/248) were health posts (fixed and mobile), 12.5% (n=31/248) were primary healthcare centres, 6.9% (n=17/248) were labour room/sexual and reproductive health units, 2.8% (n=7/248) were secondary health facilities and 16.5% (n=41/248) were other specialised care service centres. The ratio of health facilities (any) to population size was 1:3300 and the ratio of secondary health facilities to number of health facilities (any) to population size was 1:90.

| Health facility, n (%) | Home*, n (%) | Total (n) |
|------------------------|-------------|-----------|
| Neonatal death         | (23.7)      | (76.3)    | 531       |
| Stillbirth             | (27.5)      | (72.1)    | 280†      |

*Home is inclusive of deaths reported as home and community deaths.
†One stillbirth had missing information on place of death.

Our study found a neonatal mortality rate of 27.0 per 1000 live births and an estimated stillbirth rate of 15.2 per 1000 total births among Rohingya refugees in 29 camps in Cox’s Bazar, Bangladesh, between September 2017 and December 2018. Globally, countries affected by conflict, displacement and instability had the highest neonatal mortality rates in 2017–2018.7 14

DISCUSSION

We found that camps that were closer to a secondary health facility as compared with a labour room/sexual and reproductive health units had a lower mean neonatal mortality rate (p value=0.0001) (online supplemental figure S2). We found no statistically significant differences in mean stillbirth rates between camps closer to a secondary health facility as compared with those closer to a labour room/sexual and reproductive health unit (p value=0.010 and overlapping CI) (online supplemental figure S3).

Globally, in 2019, 42.0% of stillbirths were estimated to have occurred during labour.20 In general, improved care at birth has the potential to prevent almost half of...
all stillbirths in the intrapartum period. Although our study did not measure the quality of services in the Rohingya response, the lack of a strong correlation of stillbirth rates with the number of health facilities per camp and the lack of association of stillbirth rates with proximity to labour room/sexual and reproductive health units suggest that there are important factors other than simple proximity to health services that influence stillbirth rate. Further research on the quality and comprehensiveness of care provided at the health facilities and the referral pathway are needed to reduce stillbirth rate.

Our study found that when compared with camps closer to labour room/sexual and reproductive health units camps closer to secondary health facilities had lower neonatal mortality rates. This is a promising result that can inform decision on whether to scale-up the availability of secondary healthcare versus sexual and reproductive health units. The capacity to do caesarean section, labour induction and inpatient capacity at secondary healthcare level could have contributed to better quality. However, in our study, no correlation was found between neonatal mortality and the number of health facilities in a camp. This might suggest that better healthcare for prevention and management of neonatal complications need to be integrated at primary care level closer to the community.

Our results also indicated that the majority of neonatal and stillbirths occurred at home and in the community. It is likely that in the acute phase of a humanitarian crisis, where a large number of refugees have arrived in a new country, the community might have had limited contact with the healthcare system and might not be aware of where to seek care. Increase in institutional deliveries after the acute phase of a crisis have been found in previous studies in refugees camps. It is also possible that pre-crisis behaviours, low institutional delivery rates, are still in practice as underutilisation of health services by Rohingya refugees in Cox’s Bazar, Bangladesh, have been found in previous reports. Further research is needed to establish the reasons for the majority of stillbirths and neonatal deaths occurring at home or in the community. An emphasis on demand creation and dialogue with community members on the availability of services and the adaptation of service to cultural and social preferences should be explored for the Rohingya response.

Prospective community-based mortality surveillance is uncommon in humanitarian settings. In instances where it is conducted, crude mortality (all age groups) and under-five mortality are typically the outcomes of focus. While stillbirth and newborn death data can be captured through routine health information and management and surveillance systems, systems are often constrained by the health utilisation practices of the community. In this study, prospective community-based mortality surveillance was effectively implemented and provided valuable information on the magnitude of stillbirth and neonatal mortality.

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**Study strengths and limitations**

Our study has several limitations. First, the findings are not representative of all Rohingya refugee camps in Bangladesh, as data were not collected from all 34 camps. However, our study represented the majority of these camps (29/34, 85.3%). Second, while every effort was taken by the organisations to ensure complete recording of neonatal deaths and stillbirth, it is possible that missed cases or double counting due to error by data collectors, cultural and social stigma in acknowledging and reporting a stillbirth and newborn death and misrecording could have occurred. Third, the denominators of live births and total births were based on the assumption that the Myanmar crude birth rate from 2015 to 2016 have not changed, by choosing the DHS estimate, we might have overestimated the neonatal mortality and stillbirth rates. Though other estimates of crude birth rate for Rohingya refugees, including the estimate of 35.6 per 1000 people per year found in 2018 by the International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDR,B) were available we used the DHS estimate. The ICDDR,B estimate is based on a cross-sectional study of a sample drawn from 11 out of 34 camps and might not be representative, and the methodology used to calculate crude birth rate is not well described. Future studies need to consider collecting live birth data for the study period. Fourth, non-differential misclassification bias is also a possibility. Stillbirths may be recorded or reported as a miscarriage or abortion and, as a result, underestimate the true burden of stillbirths. In addition, immediate newborn deaths could have been reported as stillbirths in lieu of neonatal deaths. Fifth, our geospatial analysis included the calculation of the measurement of distance to a health facility from the geographical coordinates of the centre of camp, which may not reflect the population distribution within the camp boundaries and the true distance to the health facility. The distance from centre of camp to a health facility does not represent individual household’s proximity to a health facility. Hence, our analysis on proximity to secondary health facilities and neonatal mortality rate and stillbirth rate is ecological (camp level) and caution is needed in applying the results at individual level. In addition, the lack of information on which facilities were used by women for childbirth and neonatal care purposes might confound our results on proximity to health facilities. Finally, our study is constrained by lack of data on antenatal care, place of birth and cause of neonatal death.

Despite these study limitations, our study provides a foundation for future prospective community-based neonatal mortality and stillbirth surveillance in the acute phase of humanitarian responses. To our knowledge, our study is the first to report estimated neonatal mortality rates and stillbirth rates based on prospective community-based surveillance for the Rohingya refugees crisis in Bangladesh. Mortality estimates are vital in evaluating the benefits and effectiveness of a humanitarian
response and to inform programmatic priorities and resource allocation.

CONCLUSIONS
The results of this study indicate that neonatal mortality and stillbirth rates in Rohingya refugees in Cox’s Bazar, Bangladesh, are of concern. The possible protective effect of proximity to secondary health facilities is promising and should be used to inform future response strategies for the Rohingya setting. It is vital that programmatic activities are prioritised to increase utilisation of health services and improve quality of care during pregnancy, childbirth and the postnatal period. The ability to initiate and sustain a prospective community-based mortality surveillance system in the acute phase of a humanitarian crisis, as a joint effort of several organisations, is a promising practice for future humanitarian responses as applicable to other countries and will help improve outcome among neonates.

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Contributors RA analysed the data, drafted the initial manuscript, reviewed and revised the manuscript. JC conducted data analysis, reviewed and revised the manuscript. RA and JC did not contribute to design of the prospective surveillance and data collection. EH designed the prospective surveillance, collated data, reviewed and revised the manuscript, and is the guarantor of the study. ZH contributed to data quality and collation, reviewed and revised the manuscript.

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