Title: Improving quality of neonatal data capture and clinical care at a tertiary care hospital in Uganda through enhanced surveillance, training and mentorship.

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ABSTRACT

Introduction

Accurate documentation of neonatal morbidity and mortality is limited in many countries in sub-Saharan Africa. This project aimed to establish a surveillance system for neonatal conditions as an approach to improving quality of neonatal care.

Methods

A systematic data capture and surveillance system was established at Jinja Regional Referral hospital in Uganda using a standardized neonatal medical record form which collected detailed individual patient level data. Additionally, training and mentorship was conducted as well as provision of basic equipment.

Results

A total of 4178 neonates were hospitalised from July 2014 to December 2016. The median age at admission was one day (IQR 1-3) and 48.0% (1851/3859) were males. The median duration of hospitalization was 17 days (IQR 10-40) and the longest duration of hospitalization was 47 days (IQR 41-58). The majority were referrals from government health facilities (54.4%, 2,012/3699), though 30.6% (1123/3669) presented as self-referrals. Septicaemia (44.9%, 1962/4371), prematurity (21.0%, 917/4371**)** and birth asphyxia (19.1%, 833/4371) were the most common diagnoses. The overall mortality was 13.8% (577/4178) and the commonest causes of death included septicaemia (26.9%, 155/577), prematurity (24.3%, 140/577), birth asphyxia (21.0%, 121/577), hypothermia (9.9%, 57/577) and respiratory distress (8.0%, 46/577). The majority of deaths (51.5%, 297/577) occurred within the first 24 hours of hospitalization though a significant proportion of deaths also occurred after seven days of hospitalisation (24.1%, 139/577). A modest decrease in mortality and improvement in clinical outcomes were observed.

Conclusion

Improvement in neonatal data capture and quality of care was observed following establishment of an enhanced surveillance system, training and mentorship.

LIST OF ABBREVIATIONS

aOR	Adjusted odds ratio
CHRP	Centre for Health research and Programs
CI	Confidence Interval
HC	Health Centre
HIV	Human Immunodeficiency virus
HMIS	Health Management Information Systems
JRRH	Jinja Regional Referral Hospital
NMRF	Neonatal Medical Record form
PMTCT	Prevention of mother to child transmission of HIV
UPA	Uganda Paediatric Association
WHO	World Health Organisation

BACKGROUND

Despite substantial progress in reducing child mortality in the past several decades, improving child survival remains a matter of significant public health concern [1, 2]. Children face the highest risk of dying during the neonatal period with marked disparities in neonatal mortality reported across regions and countries. Neonatal mortality is an important indicator of quality of health care services provided to pregnant women during both the prenatal and perinatal periods, as well as care provided to the new-born immediately after birth in the delivery room and neonatal units [3, 4]. Whereas a modest decline in the neonatal mortality rate was observed between 1990 and 2016, this was slower than the decline in mortality among children aged 1–59 months; with the highest neonatal mortality rates seen in sub-Saharan Africa and Southern Asia [1]. In these settings, lack of skilled care during delivery for both mothers and neonates, coupled with inadequate basic care services for neonates at health facilities possibly contribute to these high neonatal mortality rates [5, 6].

In Uganda, an estimated 45000 neonates die each year with the national average neonatal mortality rate estimated at 21.4/1000 live births [7]. The main causes of death include birth asphyxia, infections and complications of preterm birth, all of which are preventable and treatable [8]. As is the case in many countries in sub-Saharan Africa, consistent and accurate documentation of neonatal morbidity and mortality is limited in Uganda with significant information gaps existing. Most population level maternal and neonatal mortality data in Uganda comes from demographic health surveys, verbal autopsy studies and perinatal death audits [9, 10, 11]. These approaches to collecting data are often retrospective in nature, a method known to under-report early neonatal deaths largely due to omission of events or dating errors [12]. In addition, retrospective data leads to missed opportunities for early identification of systemic challenges that contribute to neonatal deaths, which could be addressed to prevent further neonatal mortality if data were collected in real

time. The need for more frequent assessment and high-quality data, coupled with prospective analysis to develop a more accurate understanding of neonatal mortality is paramount as the general scarcity of high-quality national level data on neonatal morbidity and mortality data impairs effective planning and programme implementation.

Despite improvement over the past few years, the Health Management Information System (HMIS) designed to capture healthy facility level data does not capture sufficient data on neonatal morbidity and mortality. Currently, the HMIS captures a narrow scope of neonatal conditions and total admissions with limited information on other related clinical data on neonates. In addition, the HMIS system does not specifically report on deaths during the first month of life and most neonatal causes of death are combined in one 'perinatal conditions' category and so are not reported by programmatically useful causes of deaths [13]. Such aggregated data are not useful for purposes of understanding clinical performance and quality improvement approaches. Consequently, there is paucity of much needed high quality routinely collected data on the magnitude and spectrum of neonatal morbidity and mortality at the health facility level. There is therefore an urgent need for regularly updated data on the burden and causes of neonatal illnesses and deaths and better routine collection of neonatal information at health facilities. Such data is vital to better document trends and is useful for facility-level and national-level planning as well as monitoring and evaluation of different interventions for neonatal health.

Given that neonatal health as a global public health issue has gone from being viewed as an invisible and intractable problem, to one for which effective interventions exist and are affordable in low resource settings [14], it is critical that good quality surveillance data is available to enhance the targeting of both interventions and trainings to specific health facility or national needs. It is against this background that the neonatal disease surveillance

project was implemented with the overall objective of improving neonatal data collection and quality and neonatal health care at a referral hospital in Eastern Uganda.

METHODS

This project was implemented from July 2014 to December 2016 at Jinja Regional referral hospital (JRRH); located in Eastern Uganda. The hospital serves a catchment area including 10 districts in the Busoga sub region and two neighbouring districts located in the central region of Uganda. The facility offers specialized services for neonatal care and receives patients from surrounding district hospitals, health centre (HC) IVs and HC IIIs. The treatments available for the most common neonatal conditions at this facility included antibiotics (commonly injectable ampicillin, gentamicin, cloxacillin and ceftriaxone), intravenous fluids (including normal saline, ringers' lactate and 10% dextrose) and other aspects of supportive care including incubators, nasogastric tube feeding, phototherapy, oxygen therapy, blood transfusion services and Kangaroo mother care. HC IVs are sub-district health facilities with services for emergency obstetric care, in-patient, and outpatient care manned by one-two general doctors, nurses and midwives, while HC IIIs are smaller health facilities with basic maternity services and general outpatient care. The project was a collaboration between Uganda Paediatrics Association (UPA), JRRH and Centre for Health Research and Programs (CHRP) and was implemented in two phases. The first, between July 2014 to June 2015 constituted the pilot phase and the second phase, from December 2015 to November 2016, represented the actual project implementation period. Using a quality improvement approach, the specific aims were to set-up a surveillance system for neonatal mortality and morbidity, support the establishment of functional neonatal care points and provide health worker training and mentorship.

Baseline assessment

Prior to initiation of the project, a baseline assessment of the neonatal care points at JRRH was conducted using a modified version of the WHO tool for assessment of the quality of care for neonates [15]. This assessment aimed to understand the status of neonatal care services in the hospital at baseline with a focus on data capture and reporting systems, training and mentorship processes and needs, and equipment and supplies needs. The information from this assessment was used to identify critical gaps in the stated areas and the interventions implemented addressed these specific areas.

Surveillance system set-up

To improve surveillance of neonatal morbidity and mortality, a systematic data capture and surveillance system was established at the hospital using a standardized neonatal medical record form (NMRF) (Supplemental File 1). The NMRF collected detailed individual patient level data including patient demographics, address, referring institute, presenting symptoms and signs, obstetric history, antenatal and perinatal care details, laboratory test results, admission and final diagnoses, treatments administered, and final outcome upon discharge. It also captured information on preventive and health promotion aspects of neonatal health such as immunization, prevention of mother to child transmission of HIV (PMTCT) and feeding practices. The NMRF used check boxes to minimize transcription errors and improve on its ease of use. It also incorporated standard terminology provided for in the national neonatal care guidelines, a framework familiar to most clinicians and health care providers in Uganda. This NMRF was completed by nurses, clinical officers, intern doctors, general doctors and paediatricians. The main diagnoses were made using clinical criteria that had been developed by the hospital staff with support from the project team. These guidelines were available to the different staff completing the NMRF. Antenatal records including ultrasound scans and laboratory results were not consistently available. There was also limited access to some

laboratory tests like complete blood count, but blood culture and CRP testing were not available. Data from the NMRF was then entered into a computerized database by a trained data officer. At the end of each month, reports were generated which were shared and discussed with the staff at the hospital. The overall aim of these discussions was to highlight any improvement in performance, identify existing gaps and how they can be addressed, as well as identifying training and mentorship needs, in a timely manner.

Training and Mentorship

Training and mentorship was also conducted with approximately 30 health workers receiving training at each session. The frequency of training and mentorship sessions was determined by health facility needs with at least one session per quarter. To ensure holistic team involvement, different cadres of health workers attended the trainings, including paediatricians, medical officers, intern doctors, records personnel, senior nursing officers, enrolled nurses, nursing assistants, clinical officers and midwives. These sessions targeted all the health workers from the different neonatal care points at the hospital and focused on the common causes of morbidity and mortality and also addressed identified health systems issues. Topics and areas of training chosen were those most relevant for the identified needs of the health facility at different time points based on the data collected. To reinforce lessons from the training sessions, on-site clinical mentorship was also done and consisted of direct observations of patient care, coaching and feedback sessions. In addition, mentors also conducted teaching sessions when necessary, and these usually focussed on any emerging clinical challenges. Mentors also provided additional input on any logistic challenges identified. Training and mentorship was followed up by support supervision visits which were conducted by the project team together with regional and national officials to enhance sustainability. The mentors included senior nurses and medical officers, a data manager, paediatricians and a neonatologist.

Equipment and supplies

Equipment and supplies needs were identified through the baseline assessment and included Oxygen supply/concentrators, clinical thermometers and neonatal weighing scales. All these were procured by the project and provided to the neonatal care points to support provision of care at the facility. In addition to provision of equipment, infrastructural organization and staff coverage planning at the neonatal care points was also strengthened through provision of additional neonatal beds and mattresses and discussions on optimisation of staff duty rosters.

Quality control

The main objective of the pilot phase of this project was to provide evidence on implementation feasibility of the NMRF and also document its critical role in directly impacting on quality of care decision making. The second phase of the project additionally included two lower level facilities strategically selected to represent facilities with the largest number of neonatal referrals to JRRH, as shown by the data collected in the pilot phase. The main objective of the second phase was to further strengthen the utilization of a modified version of the NMRF and also improve quality of care at these selected lower level health facilities since poor quality referral practices had been highlighted as a contributor to mortality during the pilot phase.

This paper presents quantitative data from the surveillance system documenting the temporal trends of neonatal morbidity and mortality over both project implementation periods and describes changes potentially attributable to ongoing interventions. It also reports on the process aspects of the project according to the perceptions and experiences of the health workers.

Data management and analysis

Data were entered into EpiData version 3.1 and then transferred to STATA Version 12.1 for analysis. Any discrepancies were rechecked against the medical record. A descriptive analysis was done to document the demographic and clinical characteristics of hospitalised neonates and presented as frequencies with respective proportions for categorical parameters. Means and standard deviation (SD) were presented for continuous parameters with normal distribution and median and inter quartile range (IQR) for those that were not normally distributed. Results were presented in graphs to show trends overtime, and in tables and text. The association between death and independent variables such as gender, gestation age, location of birth, model of delivery, admission ward and referring institution was assessed using first a univariate logistic regression model to determine the crude odds ratio and 95% CI and subsequently a multivariate model adjusting for the effect of each of the independent variables to obtain the adjusted odds ratio (aOR) and 95% CI. In all analyses, a p-value of <0.05 was taken as statistically significant. For the qualitative data from health worker interviews, a thematic content analysis was conducted, and data was coded and summarized into emerging themes based on the questions asked. Verbatim quotes were used to illustrate the themes and sub-themes.

Ethics approval and consent to participate

Administrative clearance for the project was obtained from the administration of JRRH and ethics approval was provided by the JRRH Ethics committee. No individual consent was obtained as this was considered a routine health services project/audit, for which individual consent was not required.

RESULTS

From July 2014 to December 2016, data on 4178 neonates hospitalised at Jinja Regional Referral hospital was collected. The mean number of neonatal admissions per quarter was 417; with the lowest admission (287) in the last quarter of 2016 and highest (521) in the third

quarter of the same year. Data completeness over this 30-month project implementation period, defined as the absence of missing data fields or blank responses in the NMRF was generally high (> 80%). However, whereas assessment for presence of fever and failure to breastfeed achieved 100% completeness, information on temperature, Apgar score and oxygen saturation were missing for 26.2%, 40.0%, and 51.6% of records respectively. Figure 1 shows the variations in completeness for selected variables over the project implementation period. There was a general trend of improvement in data quality and completeness of data collection noted over time; for example, missing data on weight of the neonates dropped from 23.0% at the end of the pilot phase to 3.0% by the end of the second phase and missing data on admission diagnosis reduced from 43.0% in the pilot phase to 10.0% in the second phase. Such improvement was specifically noted following training and mentorship sessions in the first quarter of 2015 and after modifications of the form to simplify its use in the second quarter of 2016 (Figure 1). From the data available, the HIV prevalence rate from antenatal testing was 5.8% (191/3,092, 95% CI, 5.1% - 6.7%) and the syphilis prevalence rate was 15.4% (149/966, 95% CI, 13.3% - 17.8%).

Demographic and clinical characteristics of hospitalized neonates

The median age at admission was one day (IQR 1-3) and a higher proportion of hospitalised neonates were females (52.0%, 2008/3859). Overall, most hospitalized neonates (76.4%, 2104/2754) were delivered at government hospitals (Table 1). The overall median duration of hospitalization was 17 days (IQR 10-40) with the longest duration of hospitalization of 47 days (IQR 41-58) seen in the first year of the project, reducing to 12 days (IQR 8-44) in the last project year (non-parametric test for trends across years was significant, p=0.001). Normal vaginal delivery (63.8%, 2420/3796) was the most common mode of delivery, followed by caesarean section (35.0%, 1327/3796); (Table 1). Whereas the special care unit was the main admission ward for neonates with 1938 of 3782 (51.2%) admissions in this unit,

an approximately equal proportion of neonates (48.8%, 1744/3782) were admitted on other wards including the general Children's ward (28.3%, 1072/3782) and the postnatal ward (11.2%, 422/3782). Most of the neonates were admitted as referrals from government health facilities (54.4%, 2012/3699), but 30.4% (1123/3669) presented as self-referrals (Table 1).

Morbidity patterns among hospitalised neonates

Of the 4371 final diagnoses recorded, septicaemia (44.9%, 1962/4371), prematurity (21.0%, 917/4371) and birth asphyxia (19.1%, 833/4371) were the most common diagnoses (Table 2). Other conditions that neonates were admitted with in order of decreasing frequency included meconium aspiration (4.8%, 208/4371), meningitis (3.6%, 157/4371), hypothermia (3.4%, 150/4371) and respiratory distress (3.3% 144/4371). Septicaemia was consistently the highest cause of admission throughout the 30 months whereas there was a significant overlap between birth asphyxia and prematurity as the second commonest causes of admissions with the latter being the second commonest morbidity over the last year of project implementation. There was no significant variation in the distribution of the other causes of morbidity over the 30 months of the project (Figure 2).

Mortality trends among hospitalised neonates

At total of 577 deaths were recorded over the project implementation period among 4178 neonates admitted, giving an overall mortality of 13.8% (577/4178). The lowest mortality was 5.7% (20/349) and highest was 17.2 % (83/484) in the third and fourth quarter of the first project implementation year respectively. The commonest diagnoses associated with death were septicaemia, contributing to 26.9% (155/577) of the deaths, followed by prematurity (24.3%, 140/577), birth asphyxia (21.0%, 121/577), hypothermia (9.9%, 57/577) and respiratory distress (8.0%, 46/577), (Table 2). There was a gradual decline in mortality from the last quarter of 2014 to the third quarter of 2016 from 18.0% to 10.0% with a subsequent slight increase thereafter in the last quarter of 2016 (Figure 3).

Interesting trend patterns were observed with cause specific mortality over time. Mortality due to prematurity increased significantly over time from 10.0% in 2014 to a peak of 44.0% ($p < 0.0001$) in the second and third quarter of 2016. A similar pattern was observed with mortality due to birth asphyxia increasing from 10 % in 2014 to 36.0% ($p < 0.0001$) in the second quarter of 2016. Mortality due to hypothermia declined significantly (from 23.0 to 4.0%, $p < 0.0001$) in the third and fourth quarter of 2015 and remained low thereafter. Mortality due to the other conditions showed a non-specific undulating pattern with transient increases and declines over time. The largest proportion of neonatal deaths (45.8%, 264/577) was recorded at the special care unit which is the designated unit for hospitalisation of sick neonates. A further significant proportion of neonatal deaths (31.2%, 180/577) occurred in the children's ward which is the designated unit for hospitalisation of all sick children at the hospital. Surprisingly, 12.0% (69/577) of neonatal deaths occurred in other wards at the hospital which are not usually designated areas for neonatal hospitalizations. Mortality at the special care unit declined significantly from 55.0% at the start of the project to 30.2% during the last project quarter ($p < 0.0001$).

Overall, most deaths (51.5%, 297/577) occurred within the first 24 hours of hospitalization though a significant proportion of deaths also occurred after seven days of hospitalisation (24.1%, 139/577). Of the 523 deaths for which time of death was recorded, a significantly higher proportion of deaths occurred during the day compared to the night 58.7% (307/523) vs. 41.3 % (216/523) respectively, $p< 0.05$.

Factors associated with mortality among hospitalised neonates

Overall, there were no gender-based or gestational-age related differences in mortality (Table 3). Among the different locations of birth, home delivery was associated with a higher risk of mortality when compared to delivery at government hospitals (aOR 1.77, 95% CI 1.12-2.81, $p = 0.0015$). Delivery at a private hospital was associated with a significantly lower risk of

mortality (aOR 0.50, 95 % CI 0.37-0.69, p = 0.001). There was a slightly higher risk of mortality among neonates delivered by vacuum extraction when compared to those delivered by normal vaginal delivery, but this difference did not reach statistical significance (aOR 1.58, 95% CI 0.08-29.06). Admission on other wards other than the special care unit or the children's ward was associated with a significantly higher mortality (aOR 10.11, 95% CI 6.00-17.07, p = 0.001). There was also a significantly higher mortality among neonates referred from Health centre IVs when compared to those referred from government hospitals (aOR 1.53, 96% CI 1.06-2.20, p = 0.02); (Table 3).

Other related clinical outcomes of hospitalisation among neonates

In addition to mortality, data was also collected on other relevant clinical outcomes of hospitalisation including whether the neonate improved without disability, improved with disability, absconded or was referred to another health facility. These were considered as additional indicators of quality of care. Clinical outcomes including disability were assessed at the time of discharge. Determination of whether an infant had a disability or not was based on clinical assessment by the clinicians and this included an assessment for mainly motor function but also sensory function as appropriate at the time of discharge. Overall, the proportion of neonates who improved with disability or were referred remained very low (≤ 2.0%) throughout the project implementation period (Figure 4). On the other hand, the proportion of neonates who improved with no disability increased significantly from 14.0% to 70.0% ($p < 0.0001$) over the first three quarters of the project implementation period and remained above 60.0% throughout the other project quarters. In addition, the proportion of abscondments from the hospital decreased drastically over the first three quarters of project implementation from 78.0% to 9.0% ($p < 0.0001$), remained less than 15.0% in the second year of project implementation and was 20.0% in the last project year (Figure 4).

Health worker perspectives on the value of the project and utility of data collected

The health workers received training and mentorship on common neonatal conditions with a focus on practical skills needed for the identification, management and prevention of common neonatal conditions. The choice of training topics was determined by morbidity and mortality trends from the monthly surveillance reports and discussed and agreed upon by the health facility staff. Following these training and mentorship sessions, the health workers reported that they felt more empowered and confident to care for neonates and provide better quality care for them. These perspectives were also evident in some quotes from the qualitative interviews conducted. In response to what they thought about the project, one health worker responded saying;

"Ok, so it was a good initiative and we hope it is not ending. The system of giving us feedback was also very beneficial because people would then reflect on what they are providing in terms of quality of care."

The provision of medical equipment was also a motivator to the health workers with one stating;

"Knowing what to do when appropriate equipment is not available can be frustrating. Having the basic equipment makes a big difference."

Regarding utility of data collected, the administration and health workers were able to clearly understand the burden of neonatal morbidity and mortality in general and disease specific morbidity and mortality trends through the monthly feedback reports. Using these reports, the units were able to identify priority areas to target with existing available resources. For example, upon discovering that septicemia was a major cause of morbidity and mortality, infection control measures were strengthened through training and practice. The surveillance data also guided forecasting for drugs and supplies. For example, the requisitions to the pharmacy and stores were easier to make and justifiable because of availability of supporting information on the needs. Some local process changes were also made to facilitate improved

patient care and flow. An example was the change in the transfer process for neonates from the labor and delivery room and the children's ward to the special care unit which were streamlined, thus reducing transfer times and delays in access to care. In response to whether they thought the data had been helpful, one health worker responded as follows;

"At my level yes, because now we know the reasons for presentation to the hospital, the scope of challenges in terms of disease patterns of the babies but also we now can plan with the little information we have on how we should be ready for sick neonates. We also can now plan in terms of competencies for the health workers, we can also now plan in terms of follow up or even now from public health aspects we can plan to prevent the very conditions that are bringing them because 80-90% of these conditions are avoidable because we would be able to package a message that would help mothers that have not yet delivered so that we considerably reduce these conditions hence contribute to the reduction of morbidity and mortality".

DISCUSSION

The lack of good quality data on neonatal morbidity and mortality in sub-Saharan Africa contributes to the difficulty in estimating country-specific trends [16]. This project highlights the improvement in assessment of hospitalised neonates, data capture and data utilization following an enhanced surveillance strategy for neonatal illnesses. These results provide evidence on the feasibility of implementation of simple tools and actions to enhance surveillance for neonatal morbidity and mortality at this tertiary level of health care.

Central to the surveillance system was the neonatal medical record form (NMRF), which facilitated timely, consistent and comprehensive assessment of the neonates, and subsequent data capture into an electronic database. The NMRF ensured a holistic approach to hospital neonatal care and was easy to use by health care workers. Using the NMRF improved data collection at this health facility with a sustained improvement in data quality and

completeness seen over time with training, mentorship and support supervision. This established surveillance system also enhanced the compilation of data and analysis of trends in a timely manner and promoted regular feedback to the health workers and the administration. These data were available for audit purposes and for planning both at the unit/departmental level and health facility level. The data became a vital instrument to support changes in practise through audits and feedback sessions, both of which have been shown to be effective at improving professional practice [17] and also contribute significantly to improving quality of health care in resource limited settings [18, 19, 20]. The monthly data summaries were also a source of consumption data which was useful for quantifying needs. As a result, this contributed to improvement in forecasting of medicines and supplies and consequently to reductions in stock outs at the facility. The results therefore highlight the importance of standardized forms for neonatal clinical assessment in documenting neonatal morbidity and mortality and triggering relevant actions for improvement.

In addition to establishing the neonatal surveillance system at this hospital, the project approach to improving quality of care for neonates also included evidence-based training, mentorship, support supervision and provision of equipment. Studies done in resource-limited settings indicate that sub-standard care, inadequate training, low staff competence and a lack of resources like equipment and medication are contributing factors to neonatal death [21, 22, 23, 24]. Addressing these aspects is therefore vital to the achievement of improvement in quality of care. Indeed, clinical training has been shown to improve health worker skills and competence [25] and also have a positive impact on quality of neonatal care provided [26, 27]. To promote a more responsive approach to training and mentorship, the innovative approach used in this project was that training was mainly needs-directed, with training and mentorship needs driven by the monthly data summaries and discussions with onsite health workers. This promoted effective discussion and generation of home based or in-house

solutions to the challenges identified. Equipment needs identified through the baseline situation assessment ensured provision of equipment relevant to the needs of the health facility like thermometers, weighing scales and oxygen concentrators all very vital for neonatal care. The surveillance system facilitated a formal tracking of the impact of these interventions on multiple clinical parameters and cause specific morbidity and mortality over time, an observation often lacking in other similar studies [25]. Overall, this approach to improving quality of neonatal care at this facility incorporated multiple dimensions of the WHO quality of care improvement framework including the provision of care dimension which were addressed with evidence-based interventions to enhance routine and emergency care provision and improvement in the information systems with the enhanced surveillance which allowed for review and auditing [28]. Cross cutting areas of the framework addressed included enhancing staff competences and provision of physical resources/equipment. Following these sessions, the health workers reported that they felt more empowered and confident to care for the neonates as well as provide better quality of care.

Through this surveillance system, the true neonatal disease burden and related trends were identified. The main causes of hospitalisation were septicaemia, prematurity and birth asphyxia. These three conditions have continued to cause significant morbidity and mortality across different settings in sub-Saharan Africa despite many interventions at different care levels [29, 30]. Though the proportion of neonates with multiple diagnoses is not specifically reported, previous studies show that considerable overlap in these three conditions is common [31]. Such overlap is associated with considerable increase in mortality risk that should be addressed by effective clinical assessment and holistic management. Most neonates were hospitalized very early in life with median age at hospitalization of one day. Indeed, birth and the first day of life are times of greatest risk for both mothers and their neonates with hospitalizations in the first 24 hours of life often resulting from intrapartum

complications. As most neonatal problems present within the first day of life, early detection and intervention during this time is crucial. To ensure optimal care provision to neonates, it is vital that any risk factors are identified early enough during the prenatal and intrapartum periods, with effective communication of any potential adverse risk factors to the neonatal care teams early during the delivery process to ensure prompt treatment. The health seeking behaviour of this population may also have contributed to the early hospitalisations observed as about 30.0% of the neonates were admitted as self-referrals. It is important though to understand reasons for these many self-referrals especially if these were neonates inadequately assessed prior to discharge after delivery or whether these were predominantly home deliveries. Timely and adequate care seeking is critical to providing appropriate care to neonates at the onset of illness and avoids delays that could lead to adverse outcomes. However, care seeking for neonatal illnesses in resource limited settings appears to be low in general and remains a key challenge to improving neonatal mortality [32]. Among hospitalized neonates, the median duration of hospitalization of 17 days was quite long. Known risk factors associated with increased length of hospital stay include gestational age < 37 weeks and birth weight < 1500 grams among others [33, 34]. Prolonged hospitalization increases the risk of different adverse events such as nosocomial infections and also leads to increased costs of health care. Therefore, approaches and strategies for reducing length of hospital stay are needed. These approaches could include strengthening the links between the hospital and community and promotion of safe discharge practices especially for preterm infants.

The overall mortality was 13.8 %, which is consistent with findings from some low- and middle-income countries [35, 36], though higher than what has been reported elsewhere [37]. As neonates admitted to such tertiary health facilities are an important subgroup with a high risk of mortality, these deaths may be related to the severity of illness at the time of

admission or delays in provision of care or care seeking. The commonest causes of death were similar to what has been previously reported [38, 39] and included septicaemia, prematurity and birth asphyxia. Whereas most deaths occurred in the first 24 hours of admission, a significant proportion of deaths were also observed after seven days of admission. The first day and first week of life are a critical period as approximately three-quarters of all neonatal deaths occur in the first week of life with nearly half occurring in the first 24 hours [39, 40]. This period therefore needs to be targeted with effective interventions both at the facility and community level to improve outcomes in this age group [40]. Whereas there are effective interventions for neonatal deaths due to infections and complications of prematurity, addressing intra-partum complications is more challenging and requires improvement at all levels of the health system and interventions across the complete continuum of care.

The case fatality rate for neonatal care units in resource limited settings is highly variable and may relate to socio-cultural factors affecting treatment seeking, or health system factors affecting timeliness of referral, disease burden and quality of care provided [41]. At this tertiary care facility, mortality was significantly high among neonates delivered at home which could be indicative of insufficient resuscitation and care immediately after birth or delivery in unhygienic conditions. Promotion of hospital deliveries or skilled attendance of deliveries could prevent such mortality [42]. Similarly, referral from health centre IVs was associated with a higher mortality likely due to inadequate pre-referral treatment or delayed referral decisions. These findings highlight the need to further understand and improve the quality of care provided at these lower levels of care as well as strengthening referral systems and improving pre-referral treatment provided in these settings. Admission on any hospital ward other than the special care unit or children's ward was associated with a significantly higher mortality. These deaths may have resulted from poor thermal regulation, sub-optimal

observations, inadequate respiratory support or higher risk of infections in these non-specialised units. Surprisingly, almost 49.0% of all neonates were not hospitalized in the special care unit which is the designated care unit for neonates. Reasons for this may have been related to limitations in available beds or other hospital policies. Optimal inpatient neonatal care requires dedicated ward space, staffed by health workers with specialist training and skills [43]. Given that these specialised neonatal care points are vital in such health facilities, functional units should be made available and promoted in these settings.

Overall, a modest decline in mortality was observed during the project implementation period. Whereas different approaches were used to enhance quality of neonatal care provision at this health facility, the limited impact on mortality may be attributable to the fact that the package of interventions did not cover the complete continuum of care to include the antenatal and intrapartum periods. For more optimal coverage of these different risk periods, early identification of risk factors during antenatal and intrapartum periods, should feed into optimal planning and management of the neonates postpartum.

The strength of this project was that data collection was prospective and so provided real-time information on the morbidity and mortality trends for action. However, the approach also had some limitations. Firstly, these data only focussed on neonates admitted to the hospital, whereas this is vital, a better understanding of the whole continuum of care is critical for more optimal targeting of interventions. Therefore, including the prenatal and immediate perinatal aspects could have enriched the data further. Secondly, certain important data aspects for the neonatal period were also not captured including total births at the health facility and immediate delivery outcomes such as still births that are an important component of this neonatal period. Despite these limitations, these data do provide valuable information for planning and monitoring purposes.

Conclusions

Improved data collection and analysis in settings with high neonatal mortality is necessary for the development of cost-effective and successful programmes aimed at improving neonatal health care. These findings provide evidence for the feasibility of establishing a surveillance system for neonatal morbidity and mortality and the potential utility of such accrued data for improving quality of neonatal care. Through this system, real-time data on morbidity, mortality and outcomes of neonates admitted at a tertiary hospital were collected prospectively. These results show how routinely collected clinical data at a tertiary care facility could be used to assess and describe trends of important neonatal demographics and health indicators and also feed back into quality improvement approaches. In addition, the findings also highlight the need for additional research into the potential role of such surveillance approaches in improving quality of care provided to neonates at lower levels of care and to evaluate pre-referral care practises at lower levels of care. Furthermore, focussing on the whole continuum of care could further enhance quality of care provided and improve overall neonatal care outcomes.

DECLARATIONS

Consent for publication

Not Applicable

Availability of data and materials

The dataset analysed for this manuscript are available from the corresponding author on reasonable request. The NMRF used as the main data collection tool has been submitted as a supplementary information file.

Competing interests

The authors declare that they have no competing interests

Funding

The funding for this project was from PORTICUS. This funding agency played no role on in the design of the study, collection, analysis, and interpretation of data and in writing the manuscript.

Authors' contributions

AJ, AS, RN AM and DT conceived and designed the study and supervised data collection. SN, HN were involved in data collection and supervision of data collection. AJ and HW were responsible for data analysis and interpretation and wrote the initial draft of the manuscript. All authors read and approved the final manuscript.

Acknowledgements

We are grateful to the staff and administration of JRRH for their cooperation and support for the project and the administrative staff of Uganda Paediatric Association for the logistical support and coordination.

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TABLES

Table 1. Demographic and clinical characteristics of hospitalised neonates at Jinja regional referral hospital in Eastern Uganda: July 2014 to December 2016

Variable	Evaluation year			
	2014[1]	2015	2016	Overall
Total admissions	835	1670	1673	4178
Median admission time in days (IQR)	47 (41-58)	20 (13-30)	12 (8-44)	17(10-40)
Median age at admission in days (IQR)	2 (1 – 4)	1 (1-3)	1 (1-2)	1(1-3)
Gender[2]				
Female, n (%)	403 (54.6)	758 (51.0)	847 (51.8)	2008 (52.0)
Gestation[2]				
Term	623 (75.0)	1305 (78.1)	1321 (79.4)	3250 (78.0)
Pre-term	208 (25.0)	365 (21.9)	343 (20.6)	916 (22.0)
Location of birth[2]				
Government hospital	592 (77.2)	1164 (75.7)	345 (77.2)	2104 (76.4)
Private hospital	18 (2.4)	41 (2.7)	8 (1.8)	67 (2.4)
Private clinic	44 (5.7)	82 (5.3)	15 (3.4)	141 (5.1)
Health Center IV	57 (7.4)	148 (9.6)	50 (11.2)	255 (9.3)
Health Center III	18 (2.4)	30 (2.0)	11 (3.1)	59 (2.1)
Home	32 (4.2)	58 (3.8)	14 (3.1)	104 (3.8)
Other	6 (0.8)	14 (0.9)	4 (0.9)	24 (0.9)
Mode of delivery[2]				
Normal Vaginal delivery	472 (64.1)	966 (64.8)	980 (62.6)	2420 (63.8)
Abnormal Vaginal delivery	9 (1.2)	17 (1.1)	18 (1.2)	44 (1.2)
Vacuum extraction	0	3 (0.2)	2 (0.1)	5 (0.1)
Caesarian Section	255 (34.7)	506 (33.9)	565 (36.1)	1327 (35.0)
Admission ward[2]				
Special Care Unit	375 (50.3)	803 (57.4)	760 (46.4)	1938 (51.2)
Children's ward	221 (29.7)	402 (28.8)	449 (27.4)	1072 (28.3)
Labour ward/Delivery room	38 (5.1)	53 (3.8)	156 (9.5)	147 (6.5)
Postnatal ward	91 (12.2)	84 (6.0)	247 (27.4)	422 (11.2)
Other wards	20 (2.7)	56 (4.0)	27 (1.7)	103 (2.7)
Referring institution[2]				
Self-referral	287 (40.7)	477 (32.3)	359 (23.7)	1123 (30.4)
Health Center IV	82 (11.6)	157 (10.6)	111 (7.3)	350 (9.5)
Government hospital	286 (40.6)	778 (52.6)	948 (62.6)	2012 (54.4)
Private hospital	50 (7.1)	67 (4.5)	43 (2.8)	160 (4.3)
Private clinic	0	0	31 (2.1)	31 (0.8)
Other Health Facility	0	0	23 (1.5)	23 (0.6)

[1]Data collection from July to December 2014,

[2]Total missing overall: gender =315, gestation = 8, location of birth = 298, mode of delivery = 378, admission ward = 392, referring institution = 475

Table 2. Main causes of morbidity and mortality among hospitalised neonates at a referral hospital in Eastern Uganda: July 2014 to December 2016

Diagnosis	Morbidity (N† =4371)		Mortality (N = 577)	
	Number (%)	Rank	Number (%)	Rank
Septicaemia	1962 (44.9)	1	155 (26.9)	1
Prematurity	917 (21.0)	2	140 (24.3)	2
Birth Asphyxia	833 (19.1)	3	121 (21.0)	3
Meconium aspiration	208 (4.8)	4	24 (4.2)	7
Meningitis	157 (3.6)	5	34 (5.9)	6
Hypothermia	150 (3.4)	6	57 (9.9)	4
Respiratory distress	144 (3.3)	7	46 (8.0)	5

†Refers to total number of diagnoses recorded

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741 **Table 3. Factors associated with mortality among hospitalised neonates at a referral**
742 **hospital in Eastern Uganda: July 2014 to December 2016**

Variable	Survived N=3597	Died N=577	Crude OR (95% CI)	Adjusted OR (95% CI)	Chi p-value
Gender					
Male	1585 (47.6)	266 (50.2)	1	1	
Female	1744 (52.4)	264 (49.8)	0.90 (0.75-1.08)	0.93 (0.75-1.16)	0.52
Gestation					
Term	777 (21.7)	438 (75.9)	1	1	
Pre-term	2812 (78.3)	139 (24.1)	0.87(0.71-1.07)	0.84 (0.64-1.09)	0.19
Location of birth					
Government hospital	1816 (54.1)	290 (55.7)	1	1	
Private hospital	821 (24.5)	72 (13.8)	0.55 (0.42-0.72)	0.50 (0.37-0.69)	**0.001**
Private clinic	139 (4.1)	22 (4.2)	0.99 (0.62-1.58)	0.99 (0.56-1.74)	0.96
Health Center IV	294 (8.8)	60 (11.5)	1.28 (0.94-1.73)	1.11 (0.77-1.62)	0.57
Health Center III	77 (2.3)	23 (4.4)	1.87 (1.16-3.02)	1.65 (0.88-2.81)	0.12
Home	146 (4.3)	41 (7.9)	1.76 (1.22-2.54)	1.77 (1.12-2.81)	**0.01**
Other	62 (1.9)	13 (2.5)	1.31 (0.71-2.42)	1.33 (0.65-2.74)	0.43
Mode of delivery					
Normal Vaginal delivery	2071(63.2)	349 (67.5)	1	1	
Abnormal Vaginal delivery	35 (1.1)	9 (1.7)	1.53 (0.73-3.20)	1.22 (0.51-2.94)	0.66
Vacuum extraction	4 (0.1)	1 (0.2)	1.48 (0.17-13.31)	1.58 (0.08-29.06)	0.76
Caesarian Section	1169 (35.6)	158 (30.6)	0.80 (0.66-0.98)	1.03 (0.77-1.43)	0.83
Admission ward					
SCU	1676 (52.3)	262 (45.4)	1	1	
Children's ward	892 (27.8)	180 (31.2)	1.29 (1.05-1.59)	1.05 (0.77-1.43)	0.77
Delivery room/Labour ward	228 (7.1)	19 (3.3)	0.53 (0.33-0.87)	0.65 (0.37-1.14)	0.13
Postnatal wards	374 (11.7)	48 (8.3)	0.82 (0.59-1.14)	0.95 (0.65-1.38)	0.77
Other wards	35 (1.1)	68 (11.8)	12.43 (8.10-19.07)	10.11 (6.00-17.07)	**0.001**
Referring institution					
Government hospital	1768 (55.5)	244 (47.6)	1	1	
Health Center IV	289 (9.1)	61 (11.9)	1.53 (1.13-2.07)	1.53 (1.06-2.20)	**0.02**
Self-referral	944 (29.6)	179 (34.9)	1.37 (1.12-1.69)	1.14 (0.32-1.15)	0.39
Private hospital	142 (4.5)	18 (3.5)	0.92 (0.55-1.53)	0.60 (0.32-1.15)	0.12
Private clinic	27 (0.8)	4 (0.8)	1.07 (0.37-3.09)	0.35 (0.78-1.56)	0.16
Other	16 (0.5)	7 (1.4)	3.17 (1.29-7.78)	1.85 (0.62-5.56)	0.27

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FIGURE LEGENDS

Figure 1: Completeness of neonatal medical record forms for key variables at Jinja regional referral hospital in Eastern Uganda: July 2014 to December 2016

Figure 2: Temporal trends in morbidity among hospitalised neonates: July 2014 to December 2016

Figure 3: Temporal trends in mortality among hospitalised neonates: July 2014 to December 2016

Figure 4: Other related clinical outcomes of hospitalised neonates: July 2014 to December 2016

Figure 1:

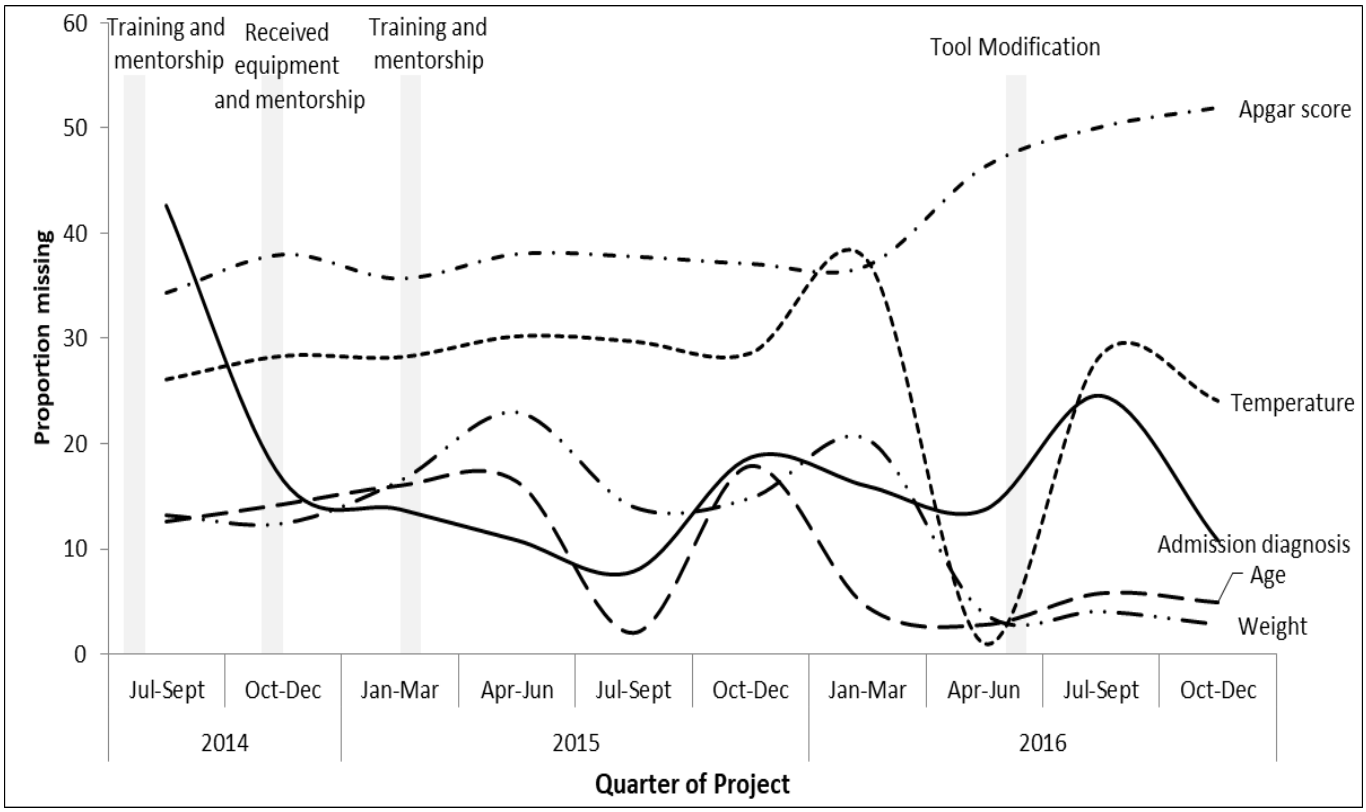

Training and mentorship
Received equipment and mentorship
Training and mentorship
Tool Modification
Apgar score
Temperature
Admission diagnosis
Age
Weight
Proportion missing
60
50
40
30
20
10
0
Jul-Sept
Oct-Dec
Jan-Mar
Apr-Jun
Jul-Sept
Oct-Dec
Jan-Mar
Apr-Jun
Jul-Sept
Oct-Dec
2014
2015
2016
Quarter of Project

Figure 2:

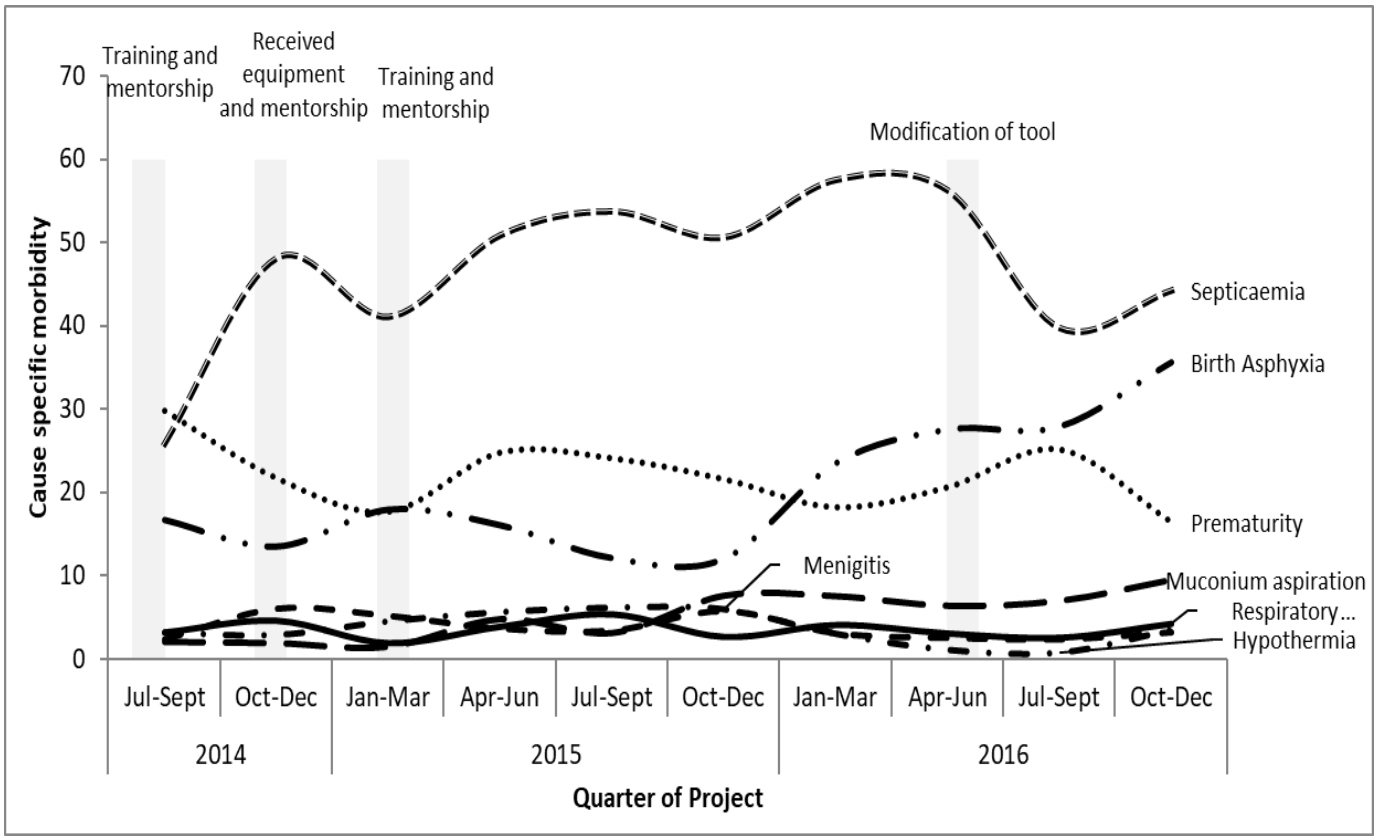

Training and mentorship
Received equipment and mentorship
Training and mentorship
Modification of tool
Cause specific morbidity
70
60
50
40
30
20
10
0
Septicaemia
Birth Asphyxia
Prematurity
Menigitis
Muconium aspiration
Respiratory…
Hypothermia
Jul-Sept
Oct-Dec
Jan-Mar
Apr-Jun
Jul-Sept
Oct-Dec
Jan-Mar
Apr-Jun
Jul-Sept
Oct-Dec
2014
2015
2016
Quarter of Project

Figure 3:

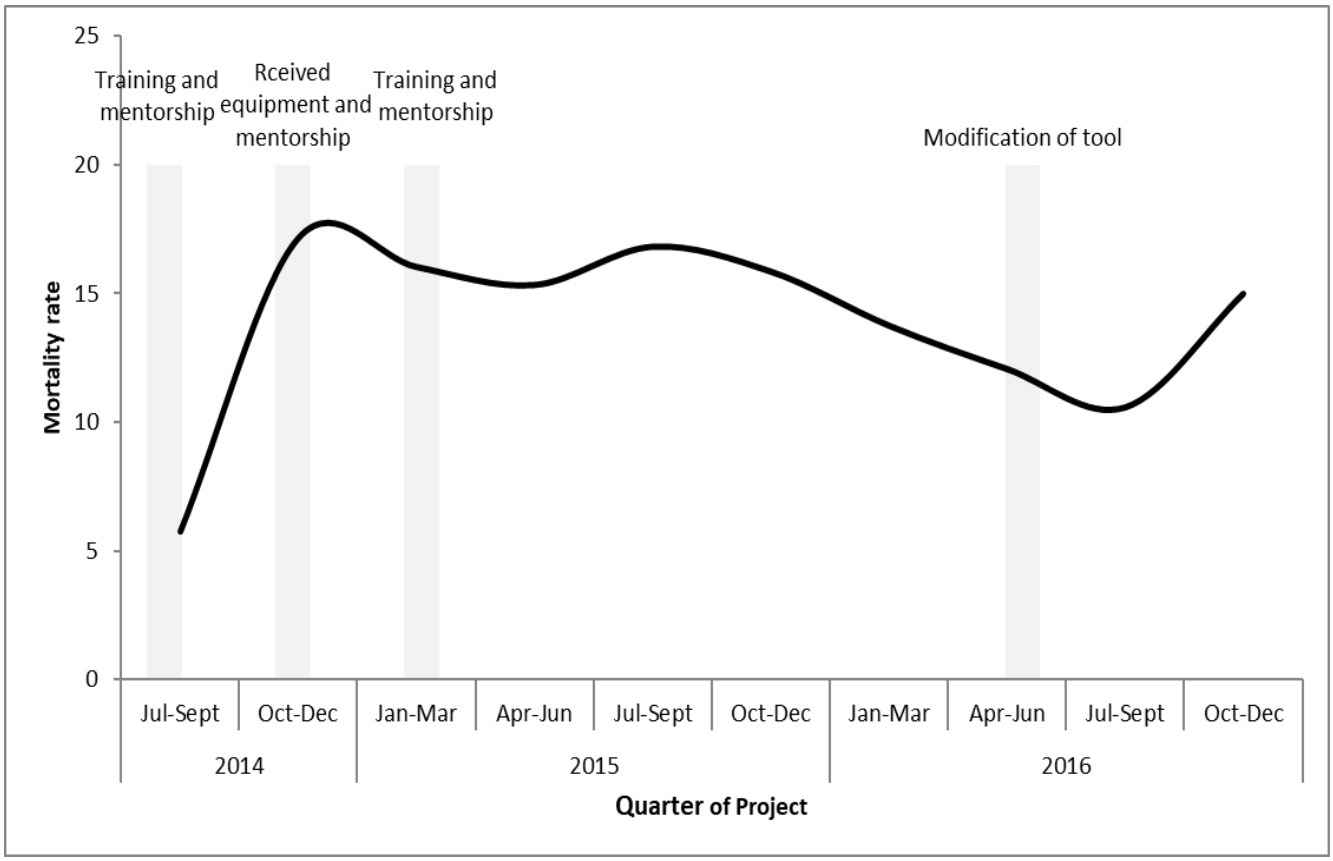
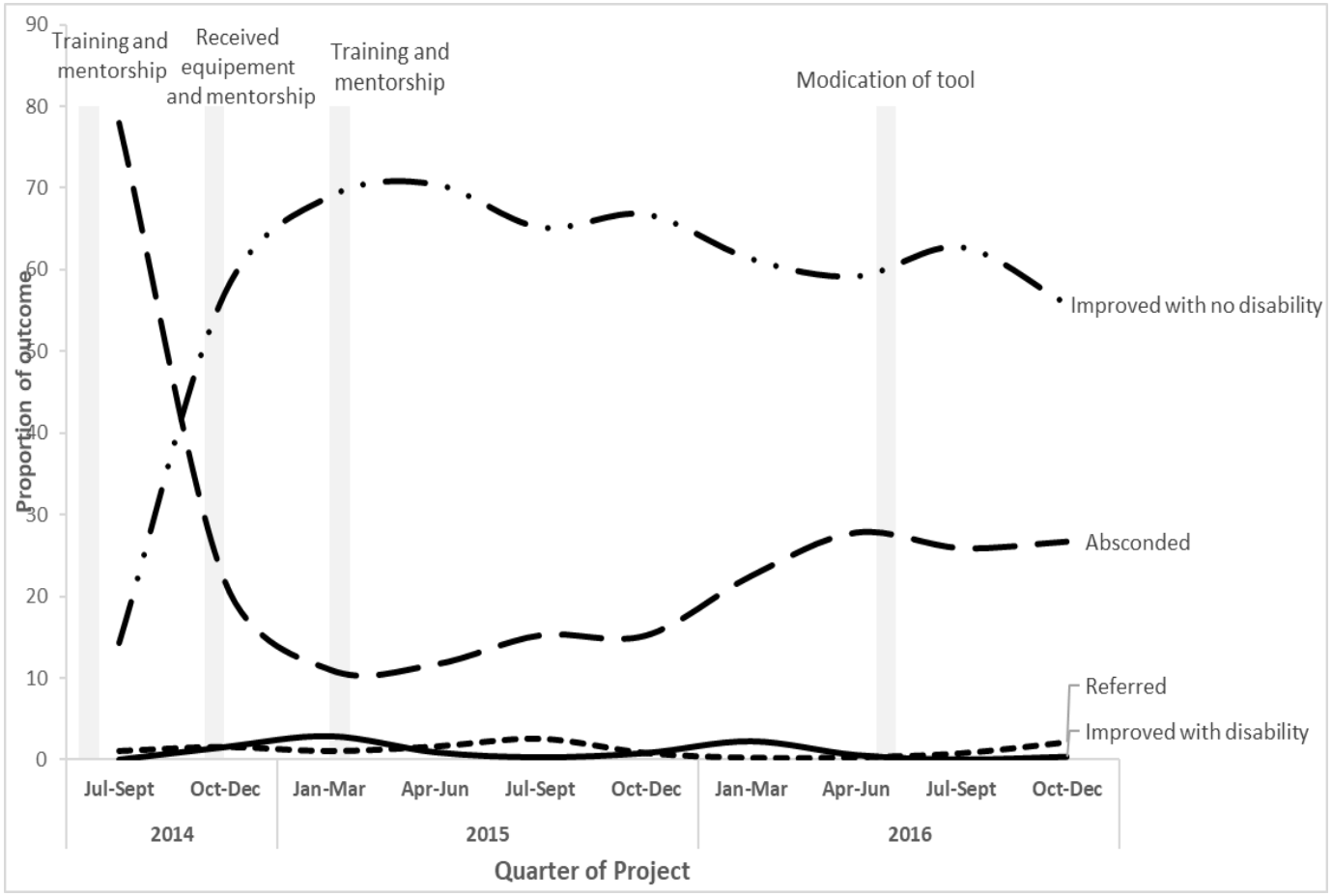

25
20
15
10
5
0
Mortality rate
Training and mentorship
Rceived equipment and mentorship
Training and mentorship
Modification of tool
Jul-Sept
Oct-Dec
Jan-Mar
Apr-Jun
Jul-Sept
Oct-Dec
Jan-Mar
Apr-Jun
Jul-Sept
Oct-Dec
2014
2015
2016
Quarter of Project

Figure 4:


Training and mentorship
Received equipement and mentorship
Training and mentorship
Modication of tool
Improved with no disability
Absconded
Referred
Improved with disability
Proportion of outcome
90
80
70
60
50
40
30
20
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0
Jul-Sept
Oct-Dec
Jan-Mar
Apr-Jun
Jul-Sept
Oct-Dec
Jan-Mar
Apr-Jun
Jul-Sept
Oct-Dec
2014
2015
2016
Quarter of Project