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.

47 **Conclusion**

48 Improvement in neonatal data capture and quality of care was observed following

49 establishment of an enhanced surveillance system, training and mentorship.

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54 **LIST OF ABBREVIATIONS**

55 aOR   Adjusted odds ratio

56 CHRP   Centre for Health research and Programs

57 CI   Confidence Interval

58 HC   Health Centre

59 HIV   Human Immunodeficiency virus

60 HMIS   Health Management Information Systems

61 JRRH   Jinja Regional Referral Hospital

62 NMRF   Neonatal Medical Record form

63   PMTCT   Prevention of mother to child transmission of HIV

64 UPA   Uganda Paediatric Association

65 WHO   World Health Organisation

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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

98 time. The need for more frequent assessment and high-quality data, coupled with prospective

99 analysis to develop a more accurate understanding of neonatal mortality is paramount as the

100 general scarcity of high-quality national level data on neonatal morbidity and mortality data

101 impairs effective planning and programme implementation.

102 Despite improvement over the past few years, the Health Management Information

103 System (HMIS) designed to capture healthy facility level data does not capture sufficient data

104 on neonatal morbidity and mortality. Currently, the HMIS captures a narrow scope of

105 neonatal conditions and total admissions with limited information on other related clinical

106 data on neonates. In addition, the HMIS system does not specifically report on deaths during

107 the first month of life and most neonatal causes of death are combined in one 'perinatal

108 conditions' category and so are not reported by programmatically useful causes of deaths

109 [13]. Such aggregated data are not useful for purposes of understanding clinical performance

110 and quality improvement approaches. Consequently, there is paucity of much needed high

111 quality routinely collected data on the magnitude and spectrum of neonatal morbidity and

112 mortality at the health facility level. There is therefore an urgent need for regularly updated

113 data on the burden and causes of neonatal illnesses and deaths and better routine collection of

114 neonatal information at health facilities. Such data is vital to better document trends and is

115 useful for facility-level and national-level planning as well as monitoring and evaluation of

116 different interventions for neonatal health.

117 Given that neonatal health as a global public health issue has gone from being viewed

118 as an invisible and intractable problem, to one for which effective interventions exist and are

119 affordable in low resource settings [14], it is critical that good quality surveillance data is

120 available to enhance the targeting of both interventions and trainings to specific health

121 facility or national needs. It is against this background that the neonatal disease surveillance

122   project was implemented with the overall objective of improving neonatal data collection and

123   quality and neonatal health care at a referral hospital in Eastern Uganda.

124   **METHODS**

125   This project was implemented from July 2014 to December 2016 at Jinja Regional referral

126   hospital (JRRH); located in Eastern Uganda. The hospital serves a catchment area including

127   10 districts in the Busoga sub region and two neighbouring districts located in the central

128   region of Uganda. The facility offers specialized services for neonatal care and receives

129   patients from surrounding district hospitals, health centre (HC) IVs and HC IIIs. The

130   treatments available for the most common neonatal conditions at this facility included

131   antibiotics (commonly injectable ampicillin, gentamicin, cloxacillin and ceftriaxone),

132   intravenous fluids (including normal saline, ringers' lactate and 10% dextrose) and other

133   aspects of supportive care including incubators, nasogastric tube feeding, phototherapy,

134   oxygen therapy, blood transfusion services and Kangaroo mother care. HC IVs are sub-

135   district health facilities with services for emergency obstetric care, in-patient, and outpatient

136   care manned by one-two general doctors, nurses and midwives, while HC IIIs are smaller

137   health facilities with basic maternity services and general outpatient care. The project was a

138   collaboration between Uganda Paediatrics Association (UPA), JRRH and Centre for Health

139   Research and Programs (CHRP) and was implemented in two phases. The first, between July

140   2014 to June 2015 constituted the pilot phase and the second phase, from December 2015 to

141   November 2016, represented the actual project implementation period. Using a quality

142   improvement approach, the specific aims were to set-up a surveillance system for neonatal

143   mortality and morbidity, support the establishment of functional neonatal care points and

144   provide health worker training and mentorship.

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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

172 laboratory tests like complete blood count, but blood culture and CRP testing were not

173 available. Data from the NMRF was then entered into a computerized database by a trained

174 data officer. At the end of each month, reports were generated which were shared and

175 discussed with the staff at the hospital. The overall aim of these discussions was to highlight

176 any improvement in performance, identify existing gaps and how they can be addressed, as

177 well as identifying training and mentorship needs, in a timely manner.

178 **Training and Mentorship**

179 Training and mentorship was also conducted with approximately 30 health workers receiving

180 training at each session. The frequency of training and mentorship sessions was determined

181 by health facility needs with at least one session per quarter. To ensure holistic team

182 involvement, different cadres of health workers attended the trainings, including

183 paediatricians, medical officers, intern doctors, records personnel, senior nursing officers,

184 enrolled nurses, nursing assistants, clinical officers and midwives. These sessions targeted all

185 the health workers from the different neonatal care points at the hospital and focused on the

186 common causes of morbidity and mortality and also addressed identified health systems

187 issues. Topics and areas of training chosen were those most relevant for the identified needs

188 of the health facility at different time points based on the data collected. To reinforce lessons

189 from the training sessions, on-site clinical mentorship was also done and consisted of direct

190 observations of patient care, coaching and feedback sessions. In addition, mentors also

191 conducted teaching sessions when necessary, and these usually focussed on any emerging

192 clinical challenges. Mentors also provided additional input on any logistic challenges

193 identified. Training and mentorship was followed up by support supervision visits which

194 were conducted by the project team together with regional and national officials to enhance

195 sustainability. The mentors included senior nurses and medical officers, a data manager,

196 paediatricians and a neonatologist.

197 **Equipment and supplies**

198 Equipment and supplies needs were identified through the baseline assessment and included

199 Oxygen supply/concentrators, clinical thermometers and neonatal weighing scales. All these

200 were procured by the project and provided to the neonatal care points to support provision of

201 care at the facility. In addition to provision of equipment, infrastructural organization and

202 staff coverage planning at the neonatal care points was also strengthened through provision of

203 additional neonatal beds and mattresses and discussions on optimisation of staff duty rosters.

204 **Quality control**

205 The main objective of the pilot phase of this project was to provide evidence on

206 implementation feasibility of the NMRF and also document its critical role in directly

207 impacting on quality of care decision making. The second phase of the project additionally

208 included two lower level facilities strategically selected to represent facilities with the largest

209 number of neonatal referrals to JRRH, as shown by the data collected in the pilot phase. The

210 main objective of the second phase was to further strengthen the utilization of a modified

211 version of the NMRF and also improve quality of care at these selected lower level health

212 facilities since poor quality referral practices had been highlighted as a contributor to

213 mortality during the pilot phase.

214 This paper presents quantitative data from the surveillance system documenting the temporal

215 trends of neonatal morbidity and mortality over both project implementation periods and

216 describes changes potentially attributable to ongoing interventions. It also reports on the

217 process aspects of the project according to the perceptions and experiences of the health

218 workers.

219 **Data management and analysis**

220   Data were entered into EpiData version 3.1 and then transferred to STATA Version 12.1 for

221   analysis. Any discrepancies were rechecked against the medical record. A descriptive

222   analysis was done to document the demographic and clinical characteristics of hospitalised

223   neonates and presented as frequencies with respective proportions for categorical parameters.

224   Means and standard deviation (SD) were presented for continuous parameters with normal

225   distribution and median and inter quartile range (IQR) for those that were not normally

226   distributed. Results were presented in graphs to show trends overtime, and in tables and text.

227   The association between death and independent variables such as gender, gestation age,

228   location of birth, model of delivery, admission ward and referring institution was assessed

229   using first a univariate logistic regression model to determine the crude odds ratio and 95%

230   CI and subsequently a multivariate model adjusting for the effect of each of the independent

231   variables to obtain the adjusted odds ratio (aOR) and 95% CI. In all analyses, a p-value of

232   <0.05 was taken as statistically significant. For the qualitative data from health worker

233   interviews, a thematic content analysis was conducted, and data was coded and summarized

234   into emerging themes based on the questions asked. Verbatim quotes were used to illustrate

235   the themes and sub-themes.

236   **Ethics approval and consent to participate**

237   Administrative clearance for the project was obtained from the administration of JRRH and

238   ethics approval was provided by the JRRH Ethics committee. No individual consent was

239   obtained as this was considered a routine health services project/audit, for which individual

240   consent was not required.

241   **RESULTS**

242   From July 2014 to December 2016, data on 4178 neonates hospitalised at Jinja Regional

243   Referral hospital was collected. The mean number of neonatal admissions per quarter was

244   417; with the lowest admission (287) in the last quarter of 2016 and highest (521) in the third

245   quarter of the same year. Data completeness over this 30-month project implementation

246   period, defined as the absence of missing data fields or blank responses in the NMRF was

247   generally high (> 80%). However, whereas assessment for presence of fever and failure to

248   breastfeed achieved 100% completeness, information on temperature, Apgar score and

249   oxygen saturation were missing for 26.2%, 40.0%, and 51.6% of records respectively. Figure

250   1 shows the variations in completeness for selected variables over the project implementation

251   period. There was a general trend of improvement in data quality and completeness of data

252   collection noted over time; for example, missing data on weight of the neonates dropped

253   from 23.0% at the end of the pilot phase to 3.0% by the end of the second phase and missing

254   data on admission diagnosis reduced from 43.0% in the pilot phase to 10.0% in the second

255   phase. Such improvement was specifically noted following training and mentorship sessions

256   in the first quarter of 2015 and after modifications of the form to simplify its use in the

257   second quarter of 2016 (Figure 1). From the data available, the HIV prevalence rate from

258   antenatal testing was 5.8% (191/3,092, 95% CI, 5.1% - 6.7%) and the syphilis prevalence rate

259   was 15.4% (149/966, 95% CI, 13.3% - 17.8%).

260   **Demographic and clinical characteristics of hospitalized neonates**

261   The median age at admission was one day (IQR 1-3) and a higher proportion of hospitalised

262   neonates were females (52.0%, 2008/3859). Overall, most hospitalized neonates (76.4%,

263   2104/2754) were delivered at government hospitals (Table 1). The overall median duration

264   of hospitalization was 17 days (IQR 10-40) with the longest duration of hospitalization of 47

265   days (IQR 41-58) seen in the first year of the project, reducing to 12 days (IQR 8-44) in the

266   last project year (non-parametric test for trends across years was significant, p=0.001).

267   Normal vaginal delivery (63.8%, 2420/3796) was the most common mode of delivery,

268   followed by caesarean section (35.0%, 1327/3796); (Table 1). Whereas the special care unit

269   was the main admission ward for neonates with 1938 of 3782 (51.2%) admissions in this unit,

270   an approximately equal proportion of neonates (48.8%, 1744/3782) were admitted on other

271   wards including the general Children's ward (28.3%, 1072/3782) and the postnatal ward

272   (11.2%, 422/3782). Most of the neonates were admitted as referrals from government health

273   facilities (54.4%, 2012/3699), but 30.4% (1123/3669) presented as self-referrals (Table 1).

274   **Morbidity patterns among hospitalised neonates**

275   Of the 4371 final diagnoses recorded, septicaemia (44.9%, 1962/4371), prematurity (21.0%,

276   917/4371) and birth asphyxia (19.1%, 833/4371) were the most common diagnoses (Table 2).

277   Other conditions that neonates were admitted with in order of decreasing frequency included

278   meconium aspiration (4.8%, 208/4371), meningitis (3.6%, 157/4371), hypothermia (3.4%,

279   150/4371) and respiratory distress (3.3% 144/4371). Septicaemia was consistently the

280   highest cause of admission throughout the 30 months whereas there was a significant overlap

281   between birth asphyxia and prematurity as the second commonest causes of admissions with

282   the latter being the second commonest morbidity over the last year of project implementation.

283   There was no significant variation in the distribution of the other causes of morbidity over the

284   30 months of the project (Figure 2).

285   **Mortality trends among hospitalised neonates**

286   At total of 577 deaths were recorded over the project implementation period among 4178

287   neonates admitted, giving an overall mortality of 13.8% (577/4178). The lowest mortality

288   was 5.7% (20/349) and highest was 17.2 % (83/484) in the third and fourth quarter of the first

289   project implementation year respectively. The commonest diagnoses associated with death

290   were septicaemia, contributing to 26.9% (155/577) of the deaths, followed by prematurity

291   (24.3%, 140/577), birth asphyxia (21.0%, 121/577), hypothermia (9.9%, 57/577) and

292   respiratory distress (8.0%, 46/577), (Table 2). There was a gradual decline in mortality from

293   the last quarter of 2014 to the third quarter of 2016 from 18.0% to 10.0% with a subsequent

294   slight increase thereafter in the last quarter of 2016 (Figure 3).

295   Interesting trend patterns were observed with cause specific mortality over time.

296   Mortality due to prematurity increased significantly over time from 10.0% in 2014 to a peak

297   of 44.0% (p < 0.0001) in the second and third quarter of 2016. A similar pattern was

298   observed with mortality due to birth asphyxia increasing from 10 % in 2014 to 36.0% (p <

299   0.0001) in the second quarter of 2016. Mortality due to hypothermia declined significantly

300   (from 23.0 to 4.0%, p < 0.0001) in the third and fourth quarter of 2015 and remained low

301   thereafter. Mortality due to the other conditions showed a non-specific undulating pattern

302   with transient increases and declines over time. The largest proportion of neonatal deaths

303   (45.8%, 264/577) was recorded at the special care unit which is the designated unit for

304   hospitalisation of sick neonates. A further significant proportion of neonatal deaths (31.2%,

305   180/577) occurred in the children's ward which is the designated unit for hospitalisation of all

306   sick children at the hospital. Surprisingly, 12.0% (69/577) of neonatal deaths occurred in

307   other wards at the hospital which are not usually designated areas for neonatal

308   hospitalizations. Mortality at the special care unit declined significantly from 55.0% at the

309   start of the project to 30.2% during the last project quarter (p < 0.0001).

310   Overall, most deaths (51.5%, 297/577) occurred within the first 24 hours of

311   hospitalization though a significant proportion of deaths also occurred after seven days of

312   hospitalisation (24.1%, 139/577). Of the 523 deaths for which time of death was recorded, a

313   significantly higher proportion of deaths occurred during the day compared to the night

314   58.7% (307/523) vs. 41.3 % (216/523) respectively, p< 0.05.

315   **Factors associated with mortality among hospitalised neonates**

316   Overall, there were no gender-based or gestational-age related differences in mortality (Table

317   3). Among the different locations of birth, home delivery was associated with a higher risk of

318   mortality when compared to delivery at government hospitals (aOR 1.77, 95% CI 1.12-2.81,

319   p = 0.0015). Delivery at a private hospital was associated with a significantly lower risk of

320 mortality (aOR 0.50, 95 % CI 0.37-0.69, p = 0.001). There was a slightly higher risk of

321 mortality among neonates delivered by vacuum extraction when compared to those delivered

322 by normal vaginal delivery, but this difference did not reach statistical significance (aOR

323 1.58, 95% CI 0.08-29.06). Admission on other wards other than the special care unit or the

324 children's ward was associated with a significantly higher mortality (aOR 10.11, 95% CI

325 6.00-17.07, p = 0.001). There was also a significantly higher mortality among neonates

326 referred from Health centre IVs when compared to those referred from government hospitals

327 (aOR 1.53, 96% CI 1.06-2.20, p = 0.02); (Table 3).

328 **Other related clinical outcomes of hospitalisation among neonates**

329 In addition to mortality, data was also collected on other relevant clinical outcomes of

330 hospitalisation including whether the neonate improved without disability, improved with

331 disability, absconded or was referred to another health facility. These were considered as

332 additional indicators of quality of care. Clinical outcomes including disability were assessed

333 at the time of discharge. Determination of whether an infant had a disability or not was based

334 on clinical assessment by the clinicians and this included an assessment for mainly motor

335 function but also sensory function as appropriate at the time of discharge. Overall, the

336 proportion of neonates who improved with disability or were referred remained very low ($\leq$

337 2.0%) throughout the project implementation period (Figure 4). On the other hand, the

338 proportion of neonates who improved with no disability increased significantly from 14.0%

339 to 70.0% (p < 0.0001) over the first three quarters of the project implementation period and

340 remained above 60.0% throughout the other project quarters. In addition, the proportion of

341 abscondments from the hospital decreased drastically over the first three quarters of project

342 implementation from 78.0% to 9.0% (p < 0.0001), remained less than 15.0% in the second

343 year of project implementation and was 20.0% in the last project year (Figure 4).

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

345 The health workers received training and mentorship on common neonatal conditions with a

346 focus on practical skills needed for the identification, management and prevention of

347 common neonatal conditions. The choice of training topics was determined by morbidity and

348 mortality trends from the monthly surveillance reports and discussed and agreed upon by the

349 health facility staff. Following these training and mentorship sessions, the health workers

350 reported that they felt more empowered and confident to care for neonates and provide better

351 quality care for them. These perspectives were also evident in some quotes from the

352 qualitative interviews conducted. In response to what they thought about the project, one

353 health worker responded saying;

354   "Ok, so it was a good initiative and we hope it is not ending. The system of giving us

355 feedback was also very beneficial because people would then reflect on what they are

356 providing in terms of quality of care."

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

358 stating;

359 "Knowing what to do when appropriate equipment is not available can be frustrating. Having

360 the basic equipment makes a big difference."

361 Regarding utility of data collected, the administration and health workers were able to clearly

362 understand the burden of neonatal morbidity and mortality in general and disease specific

363 morbidity and mortality trends through the monthly feedback reports. Using these reports, the

364 units were able to identify priority areas to target with existing available resources. For

365 example, upon discovering that septicemia was a major cause of morbidity and mortality,

366 infection control measures were strengthened through training and practice. The surveillance

367 data also guided forecasting for drugs and supplies. For example, the requisitions to the

368 pharmacy and stores were easier to make and justifiable because of availability of supporting

369 information on the needs. Some local process changes were also made to facilitate improved

370 patient care and flow. An example was the change in the transfer process for neonates from

371 the labor and delivery room and the children's ward to the special care unit which were

372 streamlined, thus reducing transfer times and delays in access to care. In response to whether

373 they thought the data had been helpful, one health worker responded as follows;

374 "At my level yes, because now we know the reasons for presentation to the hospital, the

375 scope of challenges in terms of disease patterns of the babies but also we now can plan with

376 the little information we have on how we should be ready for sick neonates. We also can now

377 plan in terms of competencies for the health workers, we can also now plan in terms of follow

378 up or even now from public health aspects we can plan to prevent the very conditions that are

379 bringing them because 80-90% of these conditions are avoidable because we would be able to

380 package a message that would help mothers that have not yet delivered so that we

381 considerably reduce these conditions hence contribute to the reduction of morbidity and

382 mortality".

383 **DISCUSSION**

384 The lack of good quality data on neonatal morbidity and mortality in sub-Saharan Africa

385 contributes to the difficulty in estimating country-specific trends [16]. This project highlights

386 the improvement in assessment of hospitalised neonates, data capture and data utilization

387 following an enhanced surveillance strategy for neonatal illnesses. These results provide

388 evidence on the feasibility of implementation of simple tools and actions to enhance

389 surveillance for neonatal morbidity and mortality at this tertiary level of health care.

390 Central to the surveillance system was the neonatal medical record form (NMRF), which

391 facilitated timely, consistent and comprehensive assessment of the neonates, and subsequent

392 data capture into an electronic database. The NMRF ensured a holistic approach to hospital

393 neonatal care and was easy to use by health care workers. Using the NMRF improved data

394 collection at this health facility with a sustained improvement in data quality and

395   completeness seen over time with training, mentorship and support supervision. This

396   established surveillance system also enhanced the compilation of data and analysis of trends

397   in a timely manner and promoted regular feedback to the health workers and the

398   administration. These data were available for audit purposes and for planning both at the

399   unit/departmental level and health facility level. The data became a vital instrument to

400   support changes in practise through audits and feedback sessions, both of which have been

401   shown to be effective at improving professional practice [17] and also contribute significantly

402   to improving quality of health care in resource limited settings [18, 19, 20]. The monthly data

403   summaries were also a source of consumption data which was useful for quantifying

404   needs. As a result, this contributed to improvement in forecasting of medicines and supplies

405   and consequently to reductions in stock outs at the facility. The results therefore highlight the

406   importance of standardized forms for neonatal clinical assessment in documenting neonatal

407   morbidity and mortality and triggering relevant actions for improvement.

408   In addition to establishing the neonatal surveillance system at this hospital, the project

409   approach to improving quality of care for neonates also included evidence-based training,

410   mentorship, support supervision and provision of equipment. Studies done in resource-limited

411   settings indicate that sub-standard care, inadequate training, low staff competence and a lack

412   of resources like equipment and medication are contributing factors to neonatal death [21, 22,

413   23, 24]. Addressing these aspects is therefore vital to the achievement of improvement in

414   quality of care. Indeed, clinical training has been shown to improve health worker skills and

415   competence [25] and also have a positive impact on quality of neonatal care provided [26,

416   27]. To promote a more responsive approach to training and mentorship, the innovative

417   approach used in this project was that training was mainly needs-directed, with training and

418   mentorship needs driven by the monthly data summaries and discussions with onsite health

419   workers. This promoted effective discussion and generation of home based or in-house

420   solutions to the challenges identified. Equipment needs identified through the baseline

421   situation assessment ensured provision of equipment relevant to the needs of the health

422   facility like thermometers, weighing scales and oxygen concentrators all very vital for

423   neonatal care. The surveillance system facilitated a formal tracking of the impact of these

424   interventions on multiple clinical parameters and cause specific morbidity and mortality over

425   time, an observation often lacking in other similar studies [25]. Overall, this approach to

426   improving quality of neonatal care at this facility incorporated multiple dimensions of the

427   WHO quality of care improvement framework including the provision of care dimension

428   which were addressed with evidence-based interventions to enhance routine and emergency

429   care provision and improvement in the information systems with the enhanced surveillance

430   which allowed for review and auditing [28]. Cross cutting areas of the framework addressed

431   included enhancing staff competences and provision of physical resources/equipment.

432   Following these sessions, the health workers reported that they felt more empowered and

433   confident to care for the neonates as well as provide better quality of care.

434   Through this surveillance system, the true neonatal disease burden and related trends

435   were identified. The main causes of hospitalisation were septicaemia, prematurity and birth

436   asphyxia. These three conditions have continued to cause significant morbidity and mortality

437   across different settings in sub-Saharan Africa despite many interventions at different care

438   levels [29, 30]. Though the proportion of neonates with multiple diagnoses is not specifically

439   reported, previous studies show that considerable overlap in these three conditions is

440   common [31]. Such overlap is associated with considerable increase in mortality risk that

441   should be addressed by effective clinical assessment and holistic management. Most neonates

442   were hospitalized very early in life with median age at hospitalization of one day. Indeed,

443   birth and the first day of life are times of greatest risk for both mothers and their neonates

444   with hospitalizations in the first 24 hours of life often resulting from intrapartum

445   complications. As most neonatal problems present within the first day of life, early detection

446   and intervention during this time is crucial. To ensure optimal care provision to neonates, it is

447   vital that any risk factors are identified early enough during the prenatal and intrapartum

448   periods, with effective communication of any potential adverse risk factors to the neonatal

449   care teams early during the delivery process to ensure prompt treatment. The health seeking

450   behaviour of this population may also have contributed to the early hospitalisations observed

451   as about 30.0% of the neonates were admitted as self-referrals. It is important though to

452   understand reasons for these many self-referrals especially if these were neonates

453   inadequately assessed prior to discharge after delivery or whether these were predominantly

454   home deliveries. Timely and adequate care seeking is critical to providing appropriate care to

455   neonates at the onset of illness and avoids delays that could lead to adverse outcomes.

456   However, care seeking for neonatal illnesses in resource limited settings appears to be low in

457   general and remains a key challenge to improving neonatal mortality [32]. Among

458   hospitalized neonates, the median duration of hospitalization of 17 days was quite long.

459   Known risk factors associated with increased length of hospital stay include gestational age <

460   37 weeks and birth weight < 1500 grams among others [33, 34]. Prolonged hospitalization

461   increases the risk of different adverse events such as nosocomial infections and also leads to

462   increased costs of health care. Therefore, approaches and strategies for reducing length of

463   hospital stay are needed. These approaches could include strengthening the links between the

464   hospital and community and promotion of safe discharge practices especially for preterm

465   infants.

466   The overall mortality was 13.8 %, which is consistent with findings from some low-

467   and middle-income countries [35, 36], though higher than what has been reported elsewhere

468   [37]. As neonates admitted to such tertiary health facilities are an important subgroup with a

469   high risk of mortality, these deaths may be related to the severity of illness at the time of

470   admission or delays in provision of care or care seeking. The commonest causes of death

471   were similar to what has been previously reported [38, 39] and included septicaemia,

472   prematurity and birth asphyxia. Whereas most deaths occurred in the first 24 hours of

473   admission, a significant proportion of deaths were also observed after seven days of

474   admission. The first day and first week of life are a critical period as approximately three-

475   quarters of all neonatal deaths occur in the first week of life with nearly half occurring in the

476   first 24 hours [39, 40]. This period therefore needs to be targeted with effective interventions

477   both at the facility and community level to improve outcomes in this age group [40]. Whereas

478   there are effective interventions for neonatal deaths due to infections and complications of

479   prematurity, addressing intra-partum complications is more challenging and requires

480   improvement at all levels of the health system and interventions across the complete

481   continuum of care.

482   The case fatality rate for neonatal care units in resource limited settings is highly

483   variable and may relate to socio-cultural factors affecting treatment seeking, or health system

484   factors affecting timeliness of referral, disease burden and quality of care provided [41]. At

485   this tertiary care facility, mortality was significantly high among neonates delivered at home

486   which could be indicative of insufficient resuscitation and care immediately after birth or

487   delivery in unhygienic conditions. Promotion of hospital deliveries or skilled attendance of

488   deliveries could prevent such mortality [42]. Similarly, referral from health centre IVs was

489   associated with a higher mortality likely due to inadequate pre-referral treatment or delayed

490   referral decisions. These findings highlight the need to further understand and improve the

491   quality of care provided at these lower levels of care as well as strengthening referral systems

492   and improving pre-referral treatment provided in these settings. Admission on any hospital

493   ward other than the special care unit or children's ward was associated with a significantly

494   higher mortality. These deaths may have resulted from poor thermal regulation, sub-optimal

495 observations, inadequate respiratory support or higher risk of infections in these non-

496 specialised units. Surprisingly, almost 49.0% of all neonates were not hospitalized in the

497 special care unit which is the designated care unit for neonates. Reasons for this may have

498 been related to limitations in available beds or other hospital policies. Optimal inpatient

499 neonatal care requires dedicated ward space, staffed by health workers with specialist training

500 and skills [43]. Given that these specialised neonatal care points are vital in such health

501 facilities, functional units should be made available and promoted in these settings.

502   Overall, a modest decline in mortality was observed during the project

503 implementation period. Whereas different approaches were used to enhance quality of

504 neonatal care provision at this health facility, the limited impact on mortality may be

505 attributable to the fact that the package of interventions did not cover the complete continuum

506 of care to include the antenatal and intrapartum periods. For more optimal coverage of these

507 different risk periods, early identification of risk factors during antenatal and intrapartum

508 periods, should feed into optimal planning and management of the neonates postpartum.

509   The strength of this project was that data collection was prospective and so provided

510 real-time information on the morbidity and mortality trends for action. However, the

511 approach also had some limitations. Firstly, these data only focussed on neonates admitted to

512 the hospital, whereas this is vital, a better understanding of the whole continuum of care is

513 critical for more optimal targeting of interventions. Therefore, including the prenatal and

514 immediate perinatal aspects could have enriched the data further. Secondly, certain important

515 data aspects for the neonatal period were also not captured including total births at the health

516 facility and immediate delivery outcomes such as still births that are an important component

517 of this neonatal period. Despite these limitations, these data do provide valuable information

518 for planning and monitoring purposes.

519 **Conclusions**

520   Improved data collection and analysis in settings with high neonatal mortality is necessary for

521   the development of cost-effective and successful programmes aimed at improving neonatal

522   health care. These findings provide evidence for the feasibility of establishing a surveillance

523   system for neonatal morbidity and mortality and the potential utility of such accrued data for

524   improving quality of neonatal care. Through this system, real-time data on morbidity,

525   mortality and outcomes of neonates admitted at a tertiary hospital were collected

526   prospectively. These results show how routinely collected clinical data at a tertiary care

527   facility could be used to assess and describe trends of important neonatal demographics and

528   health indicators and also feed back into quality improvement approaches. In addition, the

529   findings also highlight the need for additional research into the potential role of such

530   surveillance approaches in improving quality of care provided to neonates at lower levels of

531   care and to evaluate pre-referral care practises at lower levels of care. Furthermore, focussing

532   on the whole continuum of care could further enhance quality of care provided and improve

533   overall neonatal care outcomes.

534

535   **DECLARATIONS**

536   **Consent for publication**

537   Not Applicable

538   **Availability of data and materials**

539   The dataset analysed for this manuscript are available from the corresponding author on

540   reasonable request. The NMRF used as the main data collection tool has been submitted as a

541   supplementary information file.

542   **Competing interests**

543   The authors declare that they have no competing interests

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.

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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)

712   [1]Data collection from July to December 2014,

713   [2]Total missing overall: gender =315, gestation = 8, location of birth = 298, mode of delivery = 378, admission ward = 392,

714   referring institution = 475

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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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Table 3. Factors associated with mortality among hospitalised neonates at a referral 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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752 **FIGURE LEGENDS**

753 Figure 1: Completeness of neonatal medical record forms for key variables at Jinja regional

754 referral hospital in Eastern Uganda: July 2014 to December 2016

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

756 2016

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

758 2016

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

760 2016

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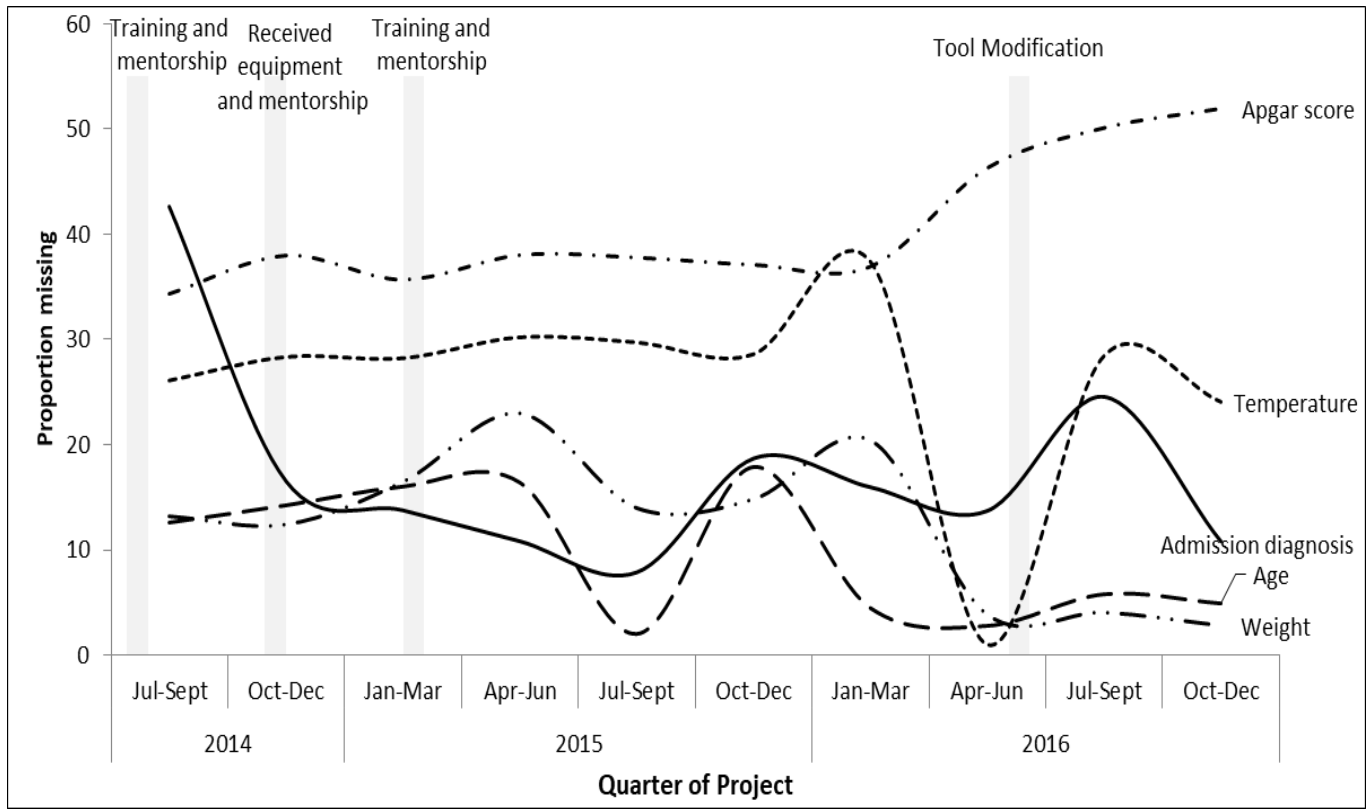765

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Figure 1:

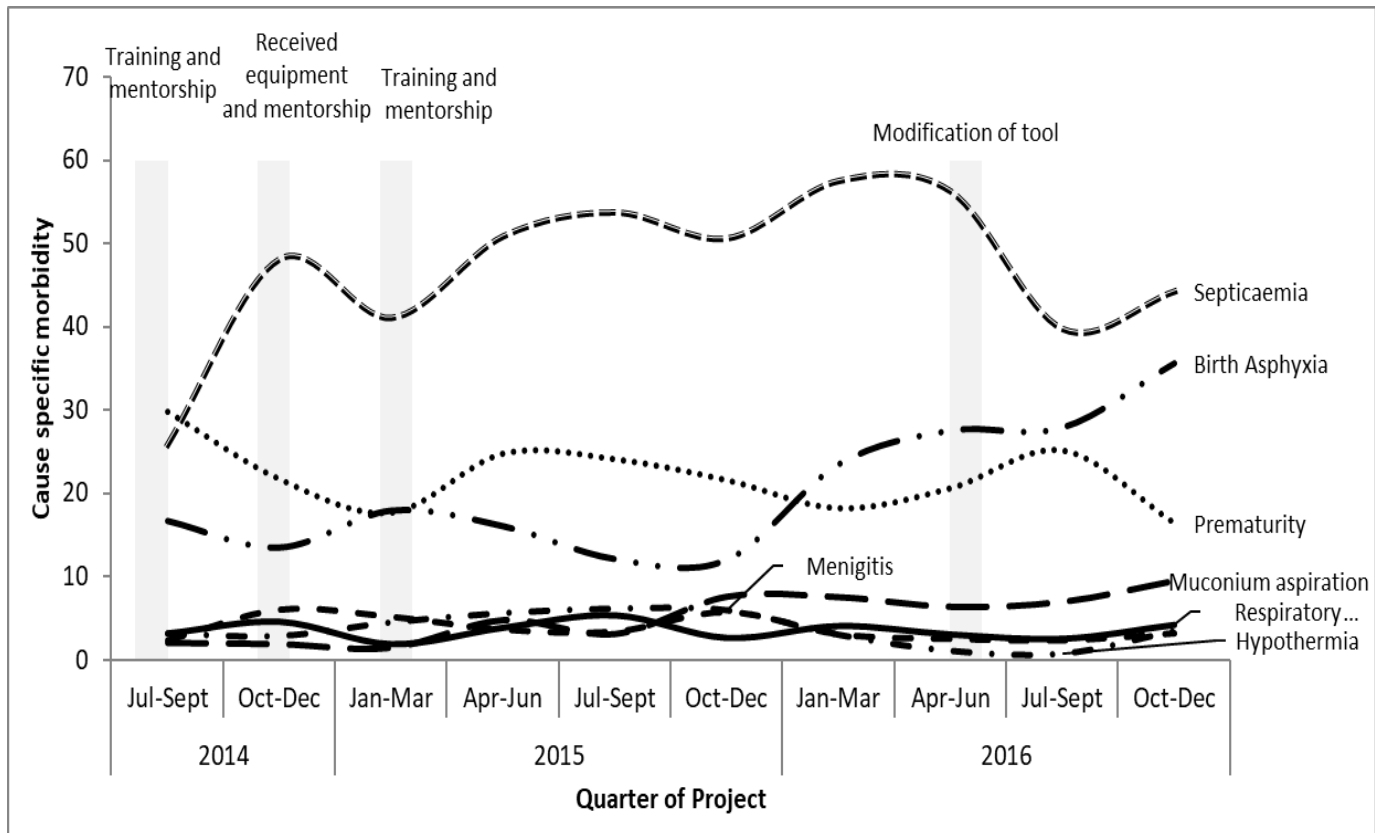
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795 **Figure 2:**

Cause specific morbidity vs *Quarter of Project*

Labels on chart: Training and mentorship; Received equipment and mentorship; Training and mentorship; Modification of tool; Septicaemia; Birth Asphyxia; Prematurity; Menigitis; Muconium aspiration; Respiratory...; Hypothermia

X-axis: Jul-Sept | Oct-Dec (2014) | Jan-Mar | Apr-Jun | Jul-Sept | Oct-Dec (2015) | Jan-Mar | Apr-Jun | Jul-Sept | Oct-Dec (2016)

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Figure 3:
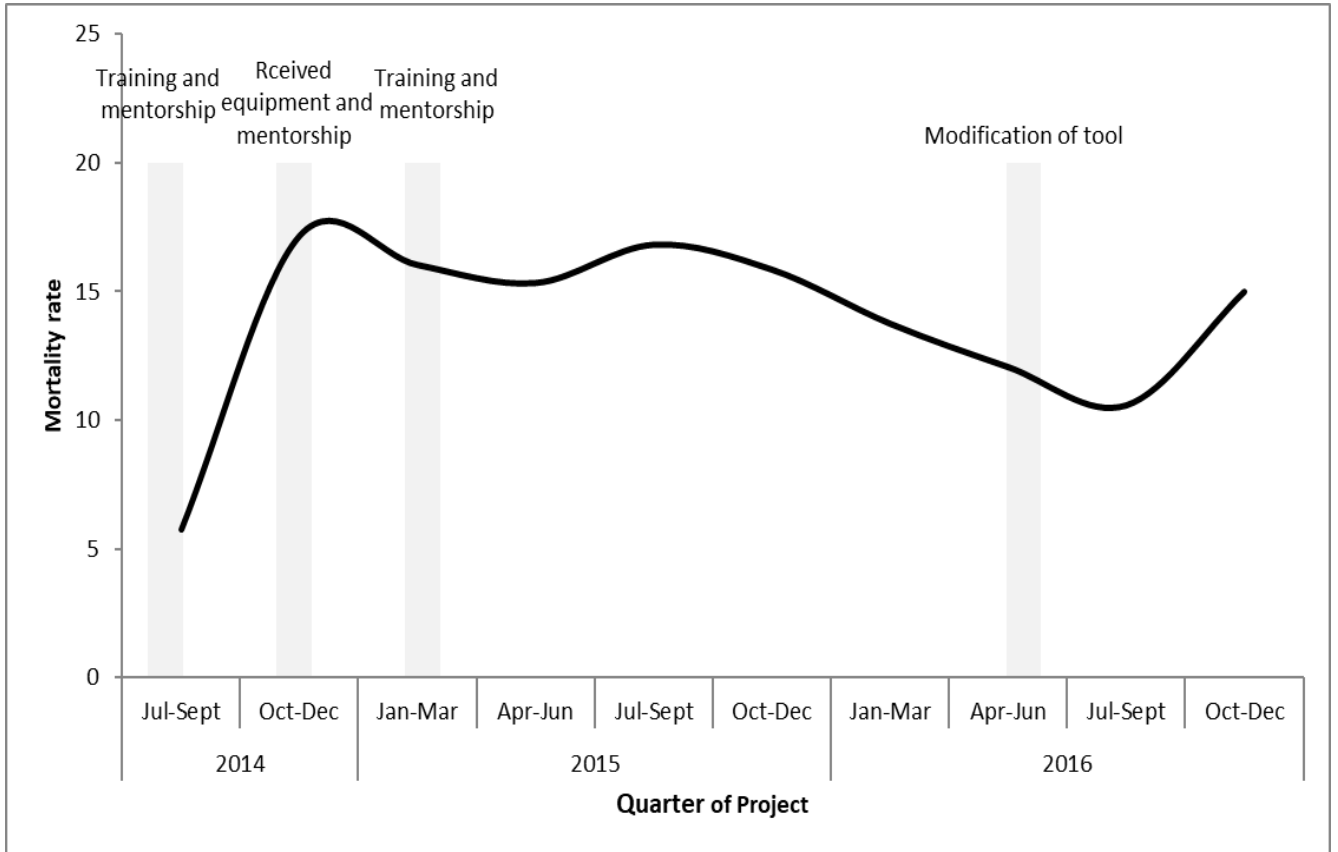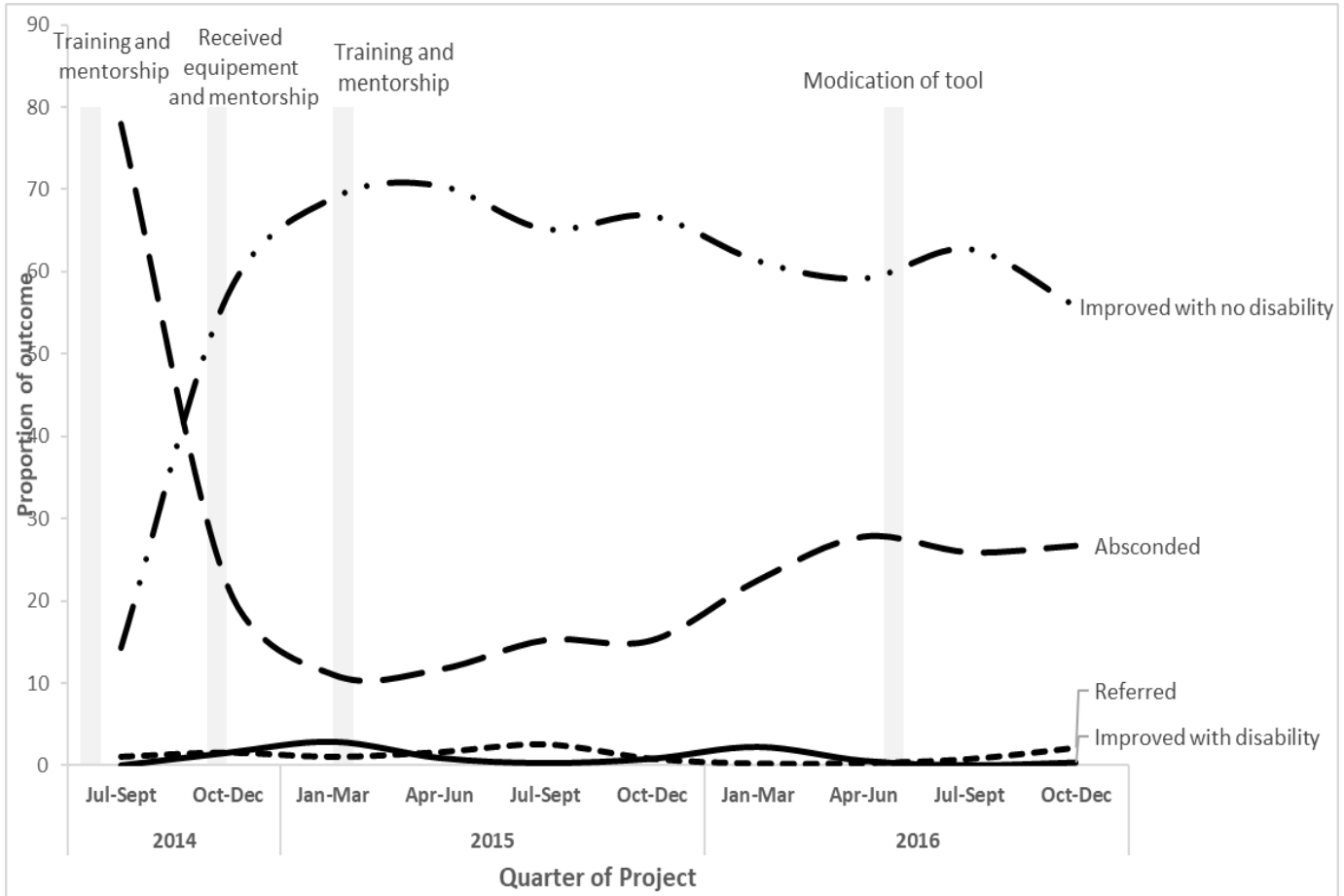

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829 **Figure 4:**

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