These are verbatim transcripts from interviews with health care providers in the NICUs at Korle Bu Teaching Hospital, Komfo Anokye Teaching Hospital, and Cape Coast Teaching Hospital in Ghana, West Africa, completed during the summer of 2015.

This was a research project associated with the Maternal and Infant Survival Study (MISS), which was conducted under the aegis of a National Institutes of Health Frameworks for Innovation training grant (1-D43-TW-009353-01). Three doctoral/post-doctoral fellows (1 from the US and 2 from Ghana) trained through the PARTNER-II program at the University of Michigan conceptualized and implemented the MISS project.

For more information, please contact [camoyer@umich.edu](mailto:camoyer@umich.edu) and reference the MISS Study in Ghana.

Type: HCP Interview-KB9002

Date: 23-06-2015

Position: House Officer

I: Ok, we will leave that right there (referring to voice recorder). Ok..Umm thank you for taking the time out of your schedule to interview with me today. Uhh so as we talked about this project is focused on learning more about babies who have life threatening complications…uh complications during and after delivery, but who survive. Your thoughts and opinions about why some babies survive while others die are very important to us helping understand these issues better. As a reminder, I will be recording the interview. This is just so that I have something to help me remember what we talked about. It also means that I won’t need to take a lot of notes, I’m just gonna probably write down stuff I wanna ask about later. Uhh so, just so you know, the recordings will never be played publicly. We will just transcribe them and then destroy the tapes. If there is anything that you don’t want to talk about, please let me know. Also, we can stop the interview at any time. Just let me know that you would like to stop. Um what we talk about will remain confidential. I won’t share the details with patients or others at the hospital. You will not be named in anything that is written about this research. Uhh do you have any questions before we start?

P: No. No question.

I: Ok. Um, so we would like to learn more about your experiences with babies that are ill and their outcomes. You have been working on the NICU for about a month now. Some of the babies have had severe complications, some of them you may have struggled with and they died. Some of them you may have struggled with and they lived. Some may have died no matter what you did. Some lived when you thought they should not have. What do you think was the difference between those who lived and those who died?

P: Can you say that again please?

I: Um just the last part or the whole thing?

P: The whole thing.

I: Oh ok. Uh, some babies had severe complications. Some of them you may have struggled with and they died. Some of them you may have struggled with and they lived. Some died no matter what you did. Some lived when you thought that they would not have lived. What do you think was the difference between those who lived and those who died?

P: Ok, I think the main difference between those who lived and those who died was the presentation. How they looked or how they appeared or the condition they came in with when they presented. Some babies for example come in with severe respiratory distress taking the preterms as an example. So by the time, and one thing we do here is sort of triaging, we immediately come we don’t even wait for the doctor to say which is the ideal thing, we send them, put them under oxygen we start check ehm checking saturations, trying IV access and others. So the main difference is I think eh the way they present. If the child is maybe more stable, maybe it’s a preterm you will expect to have apneic attacks but the child hasn’t had any apnea since it came in, breathing is fine ehm I mean yes, baby is able to, temperature control is not too bad, we’ve kept wrapped up and he’s not getting hypothermic at all. I think that is one difference. The way they present at the way we see them at presentation. I think another thing that would determine is is ehm (coughs) maternal factors or parental factors. Certain people come in with relatives, ready to do labs. Immediately you give them, “go and do this” you see them rushing to come and they only parents allowed in here, so they go ahead do the labs bring the bottles for samples, start buying medications. Others cant find any relatives [cutout-3:47]. Probably there’s one that I think delivered in a taxi, the parents came and then now we couldn’t find the mother. They said they would bring a number of relatives and we couldn’t get in touch. You can imagine in such a situation you have to use all we have at our disposal because when you don’t have enough funds to go ahead and then buy, if we have funds, resources everyone has their work schedule. I think that’s another main thing they (sucks teeth) uhm relatives or whoever comes in, the willingness to do labs or willingness to take active part in whatever is happening to the child. I think the, a uh third reason I will add is the staff. The staff are really committed. More nurses and ehm doctors have been trained in resuscitation. So that why I said even though a doctor has to see and still do this, and put under oxygen, the nurses here with their years of experience, I’m just a month here (phone rings) but we see that most of them have worked here over the years and then they know, they could tell, this baby is blue, this baby is asphyxiated this baby is having a seizure, this baby is getting tachypneic or just dyspneic So lets just start oxygen, lets monitor the RDS, lets monitor saturation, lets monitor monitor temperature and then see that’s also improves outcomes so what I say for this one.

I: Ok. Uh can you tell me about your experiences with those babies who lived when you thought they were going to die? What diseases or conditions did these babies have?

P: Ok, I’ve seen, maybe I’ll just say one so far. This is an extreme preterm that was at I think 27 weeks old, 28 weeks, 28 weeker, who you know difficulty with respiration, difficulty breathing and has been ehm I came to meet her here actually was on oxygen for a long time, went on to CPAP, we wean off of oxygen, now was breathing spontaneously. And then all of a sudden there was a day I mean he picked up so nicely, there was a day when we all went during our rounds, look at this baby has stopped breathing. And then everyone rushed and then we started bagging for almost 2,3 hours and you mother is coming here every three hours to feed from six til six. So mother came and see that’s what they know. They know that once we start bagging, prognosis isn’t good and we don’t want to do it when its feeding time. So mother came in and saw this child and went back because I think she thought all hope was lost. She kept coming in to spy, kept going and coming to spy. By God’s grace this child lived. We moved his, he started responding, we moved onto CPAP and he picked up and today he is there breathing spontaneously, so I think we call him our miracle baby I think. I don’t I really don’t know what happened or, yeah but I think that is it. We didn’t expect that child to make it we all said oh we need to start counseling the mother which we actually did and as I said when they come in they see us bagging, they know the prognosis is poor because its one big cubicle, they all come in to sit in and feed. But I think it really got all of us excited and now we are trying to increase feeds this child is having so that child can gain weight and then he is doing very well as we speak. He’s breathing spontaneously, he tolerating feeds, eh its just about him I say catching up, making the extra effort. I hope I’ve answered the question.

I: Oh yeah.

P: At a point I thought I was deviating (laughs).

I: (laughs) Um, was any special care given after, now that the baby is doing better and things have resolved do you give special care?

P: Special care, we are trying to do KMC, you know KMC? Kangaroo Mother Care. Where the child is put, there is skin to skin contact between child and mother and child, which enhances eh like sort of, it prevents apnea because the mother’s heartbeats sort of simulate, there is such close (phone rings) proximity between mother and child so instead of the regular times that the others come and do it, mother is given more time, she is given also more time to express because now we are feeding, bath, and the ?(reviews)? are more often, so that child can tolerate more. So I would say that is the special care we are giving to her. So that is also enhancing bonding between mother and child we call that [inaudible-8:29] to enhance her milk production and then I think enhance the chances of survival of this little one. Giving mother some confidence as well, cause knowing that they are so tiny, they are even afraid to handle them.

I: Mhmm, are mothers typically given special instructions for caring for babies that lived that you thought were going to die?

P: Well, yes, they are. They…first of all, using the preterms as an example, that is the commonly normal ones we see. We tell them, we give them some medications [inaudible-9:08] to prevent apneic attack, we give them micronutrients to enhance growth, to enhance their immune systems function. We also tell them, we teach them feeding by cup and spoon. So we make sure they are confident before we let them go home, however if mother goes home [cutout] and realizes child is not gaining weight, adequate feeding, breast feeding, I mean low production for child to feed its not enough. Or she’s having any difficulties she shouldn’t hesitate to come back here if, and then the usual ones, maybe child is febrile, child is not feeding well, I mean anything that’s she sees that’s odd. Whatever we were doing here, the way the condition of the child when he was discharged, if she realizes that things aren’t the same, she should immediately inform us so that we know.

I: Um, what cultural barriers do you think exist when it comes to giving instructions to the mothers?

P: Cultural barriers, I think ehm, maybe language. Language. You know, some of these people are from the north. This a teaching hospital, referral site. So people come from every corner and they come without any relative. Probably just with the ambulance driver and then one or two relatives who are also from the same region. They can’t speak your language, so interaction with them “do this, do that, buy medication, do this” becomes a problem. We try as much as possible to get stuff or patients who are from the same ehm religion or ethnic group to communicate. I know what a patient is saying and then what a doctor is saying they may misinterpret it and since you can’t understand then this is what you go with. And ehm yea so far that I don’t think there is any other cultural one, like I say maybe people who don’t accept transfusions, blood and blood products, haven’t come across in many years, so I think more of language barrier.

I: Ok. Have you ever discussed one of these cases of babies that survived when you thought they should have died with your supervisor?

P: Well this one I may, I keep mentioning or using as an example, it was sort of a team effort. I haven’t gone ahead to do any further discussions with any of them. This was something that we all participated in when child was coming apneic and sort of about to die. And we all mobilized our efforts or, I haven’t gone further to ask or inquire about anything different.

I: Ok, um cases like this commonly discussed amongst your team?

P: I don’t think so. I don’t know and I don’t think so.

I: Um

P: What usually goes on is we have eh you know as we said, there are ranking there there is a hierarchy so if there something you dont [cutout-12:20] you are handing over very morning. So if there is a problem, we share and then we see how we can tackle this, especially if the immediate superior supervisor cannot handle it perhaps too maybe a particular setting with these are discussed, I’m not sure we have any such thing.

I: Um, so when, during those kinds of discussions, like during the rounds and stuff, what is usually the outcome of the discussions that you have about the cases you are having trouble with?

P: We make a plan and then we task everyone. We want for our eh random blood sugar checks we can tell the nurses, serve as a reminder we place it on the incubator and then we keep reminding “don’t forget this, don’t forget that, I want continuous SpO2 measuring.” We used to have monitors, but now some are faulty so we have the monitor attached to the child’s foot so it will be reading and it beeps so you be reminded that there’s something I have to check up on and then maybe the House Officer will go and get some blood or go and chase this lab. They go and chase the mother on the ward, get her to go and pay for this lab or go and collect the lab from the sample. So we, so we make a plan and then we task everyone with whatever they have to do. And since that child will be critically ill at that point it and so it’s like at the back of your mind the whole time. So the least time you get to go check up on the child, check up on the child. Then you keep reminding the others of what they have to [inaudible-13:54], random blood sugar check we keep prompting the nurses, sometimes we even have to get up and do it yourself or SpO2 saturation you have to check on it. The heart rate, the pulse rates, all those things. As for medications, we make sure they are getting it. If there is any ehm bolus or infusion we have to give, we sort of do it. So plans, we make plans and then we affect them immediately so if it means not proceeding to the next patient because you have to do eh stuff on that particular one you do it before you move on.

I: Mhmm. Ok. Have you ever received formal training on how to handle cases of babies that survived when you thought they would’ve died?

P: No. I have not received any special training on that.

I: Ok. Um do you think there should be more training on how to handle?

P: I think there should be because this one I’m using for example, this child survived, we all thought he had died but then what next? We keep going everyday, we see he is breathing fine he’s feeding fine but we don’t go or I don’t go the extra mile to find out about maybe other things I should look out for [cutout-15:19] damage or damage to any other organ. I don’t have any training in that so I wouldn’t go the extra mile looking for any of that but if we had some sort of training then you would know this child looks fine now but what if in the future its going to effect growth, its going to eh and then you anticipate and then you make it a more interdisciplinary approach. Before child is discharged you can tell mother immediately child is this, we start with this. And you prepare her mind so that when child is growing she won’t start complaining of finances and time and all that because to her the child may seem fine but you don’t know but you anticipate in the future.

I: Um what do you believe is the most important thing to understand in order to handle these kinds of cases?

P: The most important thing is… there is no time. Time is the em, time …I don’t know how to put it. Let’s say time waits for no man. So action. The most important thing is action. You shouldn’t lag behind or once, as I say, you assign people to do certain things, you hope and wait that they’ll do it. It should serve as a constant reminder. If someone is not up to the task you get up and then do things yourself. That is the most important. You should be proactive, you shouldn’t—maybe that is the word, proactivity. You shouldn’t wait for others, I’ve told the nurse to do this, so if she is not doing it and I also relax because that isn’t my job. It doesn’t take anything for me if you set up infusion, if you give administer the medication, if you check the random blood sugar. I think time is of the most importance as well one’s proactivity, so, what one is doing. You have your bosses there, if you are not comfortable, you can’t remember anything, you can always complain can always ask and then go ahead then do it. So that, I suppose.

I: Ok. What do you believe is the most important thing for mothers to understand when they’re, once they’re taking these kinds of babies home?

P Patience, I think is the most important thing. Because you realize that sometimes feeding these children it takes hours, maybe erh, I would baby to the breast, in a couple of minutes we are done. I put baby down and then I’m off I have to do other things. But this baby who can’t suck, sucking reflexes and they has to be cup and spoon fed and you should see the size of the spoon. It’s taking virtually, I don’t know if point (.)1 mils (/mL/) at a time so how long, you are feeding this child 30 mils (/mL/). You should be very patient, very very very patient. You should have family support, people who help you, people who encourage you. Here [cutout-18:10] forced to sit down and do it you child has been admitted. When you go home you may get frustrated, you may get tired, you have your daily work you do which is bringing at least money to the family. So I think it’s patience, patience is the most important thing that they patient’s parents should be taught before they go. Because it isn’t easy, sometimes when they are taking so much time the nurses take over and then do it. Eh at home who is going to take over? That’s your child. If you don’t do it no one else will, probably your mother, the child’s grandmother and even that, for how long? So yes, its patience.

I: So yeah, you mentioned family support, what, what role do you feel like family support plays in the babies surviving once its discharged?

P: They are some mothers, especially the teenage mothers who are not comfortable with their handling their babies, let alone child is preterm. There was one we had here, child was being discharged to mother, mother said “no” she wanted her mother, that’s child grandmother to come to be taught whatever she had been taught, the care she had been taught, before she would be comfortable enough. I tell that baby fell 1 kilogram, 900 gram they are not comfortable handling such, of course we won’t discharge a 900 gram baby but lets say even 1.4, 1.5, some are not comfortable handling them. But seeing that my mother who took care of me, can handle or could have handled me, could’ve handled my sibling, she’s in a better position to handle the 1.5 gram [/kilogram/] baby. So that’s the supports the families give the um mostly the grandmothers. And as I said it’s most common with our teenage mothers who are in themselves, I was going to say, children. So they also need some support, it’s basically the grandmothers who can get at this. Having aunties and other family friends who are also very supportive. So with these people I mean you know that when she goes home and she can’t do it, she’s scared, at least maybe the first month, mother is there, grandmother is there to help, so she’s a bit more confident or comfortable.

I: Um, are you familiar with the term near miss?

P: No, I’m not familiar with it.

I: Ok. Um, so a near miss is when a baby looks like they’re not gonna make it, like they’re probably going to die but they survive. So basically what we have been talking about. Um, do you think providers all have the same idea of what a near miss is?

P: Survivors?

I: Uh, like health care workers.

P: Um, I’m not sure they uh this education or if we explain to them it’s important as it has been explained to me, we would know. It may sound like it is an ambiguous thing but I’m not sure if others would know too much.

I: You think um, having that distinction of a baby that’s had a near miss versus a baby that didn’t, do you think that this distinction is useful?

P: Yes, I think its very useful and very yes very useful because it’s going to make sure that the healthcare providers pay, we should pay particular attention to a baby of course this is an intensive care unit. Ideally, one patient to one medical professional but if you know that this is a near miss for example, you nurse this child very carefully, cautiously. Literally you are leaving the cubicle at a certain time you have to hand over that this child needs special care, this child you should keep an eye, close eye on this child the whole time. So I think its even going to enhance that child’s survival rate, ‘cause you know that probably child can stop breathing at any time and we need bag and mask and so you have your resuscitation tools right I mean at um arm’s length or at a point where you don’t have to go searching where is this, where is that? I think its going to provide and enhance the care of those ones who are near misses to prevent us from missing them actually.

I: If you knew a baby was classified as having a near miss event do you think it would change how you managed that baby?

P: Yes, it would. It would change how you managed the baby. As I said you are going to be extra careful because you don’t want it to be a miss this time. It’s been a near miss the first time, but next time could have you could actually miss it totally. So you are going to give that baby extra care, extra support. If it means putting the child in a incubator where immediately you lift your head you might see whatever because the incubators are see through. That’s one purpose, so that you can see whatever is going on. So I think its going to improve the care we give to these babies anyway and eventually improve their survival, which what we want.

I: Right. Um what challenges do you think that babies who experienced a near miss will face as they age?

P: …Well, I think they will probably be some… should I say maybe some brain malfunctionong. Cause I was just talking about further evaluating and then taking ehm, require long term support for this child, maybe it would even be a multidisciplinary, maybe there could’ve been some brain dam-[cutout]. There could’ve been some brain damage there could have been other organs that could have been damaged but in the interim baby looks fine, he looks stable so you think all is well. I think these are some of the things that may be there but you will not know what they are until eventual… I mean long term support will tell.

I: And how do you think the healthcare system will respond to their needs?

P: We have to make it multidisciplinary as I was saying, that’s the only way. So immediately you are discharged, let’s say the child will be attending the NICU clinic, intensive care unit, when we discharge you, we review you there up until a certain age. So in this child’s case we won’t discharge you, we’ll refer you, continue with this specialty, maybe go to the neurodevelopmental clinic or go to the renal clinic supposing he has some renal impairment, go to the psychologist or go to the psychiatrist or go to the speech or hearing therapists, depending on where we fall short, then we follow you up from there. And even that, when you go you have to come back and then give us feedback because it’s with that feedback that if we have other babies presenting in a similar situation like yours (phone rings) then we can know what action to take and what plan we have to take or probably there was a specialty we didn’t involve, maybe an ophthalmologic problem, and then we realize that next time we add an ophthalmologic assessment to the babies we are following up in the long term.

I: Ok, so that’s…it for my list of questions. Do you have any other comments you want to make about babies that almost died but lived just in general that you think pertains to this study?

P: Uh my…the main thing I will say is about eh the preterms because that’s, most of them they usually come in or they fall under this category of the near misses, the preterms. And sometimes its by no fault of the theirs, you know. You may see a preterm delivered because of severe preeclampsia or eclampsia or some maternal condition that the baby has to be delivered so that it can make it and sometimes it’s to the detriment of the baby. You can’t do anything about it but we have to be extra cautious and extra careful. We put plans so all structure is in place, lets say if you know you are going to deliver the baby early, at that date, we give steroids to help with lung maturation and others. But we should also pre-inform the parents that once this baby is going to be born earlier than the time, most likely he will need long term care. He will be in the intensive care unit for a while when you discharge you are discharged, this and this is what you are going to go through you will not be discharged and you will be coming for routine clinic visits. So we should prepare the minds of the parents and the patients and we should also give them the prognosis, counsel them that we are taking baby out early so it may or may not survive. These are the chances. Its not all up to us and that’s what we could I think. So these are the things we could do. So educate parents and these preterms and then encourage them as well. I think that could be a good point.

I: Alright [cutout-27:35], thank you for your time for answering the questions. We hope your answers will help us understand more why babies survive [crosstalk]

P: I hope so too.

I: So we don’t miss them. Um so please let me know, do you have any questions now that we’re done?

P: Eeeehm no. So you I just noticed that it’s a study from three universities in Ghana. It’s just in Ghana? This study is just in Ghana? Ok, but is there any collaboration between us and you. Cause I hear you are coming from the University of Michigan.

I: Mhmm yes, so one of the prinicipal investigators works at the University of Michigan

P: Ok.

I: But we are not doing the study in…Michigan.

P: Just in Ghana.

I: Mhmm.

P: So a period of how long is it?

I: Umm they have already been collecting data for about 3 months. I think at least for a couple more months and then theres gonna be a follow up in a year. So they are doing um they’re collecting data on near misses and seeing like how eh a tool on identifying babies as near miss what does that help with.

P: Ok.

I: Um so yeah so then they’ll do a follow up and see from there what they found. So were doing these interviews to kinda see um what are the opinions of near miss amongst like the actual people that deal with [crosstalk]

P: So ok, I hope my answers have been helpful.

I: Yeah. And also I can say for the interview, the interview ID is KB9002. Just so I know when I’m listening who this is. Um and so if you have any questions you can just, I can give you my email if you want it. Uh also if you want a copy of this consent form [cross talk] we can get you one but we’ll always have it on file for uh a few years after the research study is completed.

P: Ok.

I: So just let me know.

P: Ok.

I: Alright.

END OF INTERVIEW

Type: HCP Interview-KB9004

Date: 25-06-2015

Position: Nurse

I: Ok so, uh thank you for taking time out of your schedule to meet with me today. As we discussed this, well as I think people told you, what this project is about but just in case, uh this project is focused on learning more about the babies who have life threatening complications during and after delivery, but who survive. Your thoughts and opinions about why some babies survive while others die are very important to helping us understand these issues better. Uhh, as a reminder, I will be recording the interview. This is just so that I have something to help me remember what we talk about. It also means that I won’t have to take a lot of notes. I’m just taking notes to remember what to follow up on and ask you about. Just so you know, these recordings will never be played in the public. We will transcribe them and then destroy the tapes.

P: Ok.

I: If there’s anything that you don’t want to talk about, please let me know. Also, we can stop the interview at any time. Please let me know if you would like to stop.

P: Ok.

I: What we talk about will remain confidential. I won’t share the details with patients or others at the hospital. You will not be named in anything that is written about this research. Um and just so the recording knows which interview this is, this is KB9004. So, um we would like to learn more about your experiences with babies who are ill and their outcomes. You’ve been working in the NICU unit for some time now. Uhh and you’ve seen some babies that have had severe complications. Some of them, you may have struggled with and they died. Some of them, you may have struggled with and they lived. Some died no matter what you did. Some lived when you thought that they would not have lived. What do you think is the difference between those who lived and those who died?

P: Mhmm, I think the condition at which they come. Some come with very serious um conditions, sometimes complications even set in before they come. But some too they are brought earlier on so then that helps in their survival rate. So it’s the condition in which the baby will come. And I think the time at which it was detected. Sometimes some, I don’t know if you in the advance countries, they have the reading and there some tests that are that is carried out so that if there is something with the baby even whilst the baby is still in the womb or mother’s uterus they can detect it. But here in most cases its its not detected cause some mothers who are not able to come for antenatal due to financial constraint. So before they come in it’s the stage at which they come and the condition in which the child presents so…I think that’s the difference.

I: Um, can you tell me about your experiences with those babies who lived when you thought that they were going to die? What diseases or conditions did these babies have?

P: Mmm, the preterm babies and also birth asphyxia babies sometimes some of the preterms they are so small; they come in ehm respiration is very bad we think oh this baby, maybe might not make it but then we check [cutout-3:38] and if eh other equipment we have at that moment is suitable for baby mostly they survive. But then some of them too, the condition is not so is quite bad but then something like ventilator. Yesterday we had one baby who was saying if we put we could put that child on a ventilator its likely baby could make it but then there is none on the ward so. But still that baby’s alive but then it means any moment maybe that child we could, we’ll lose him because we have to do manual ehm we have to be resuscitating manually but not on gadget or equipment that were suppose to use so that’s it that I know.

I: Um, for these babies are any special care given after their condition is resolved?

P: After their condition is resolved? Is it when they are discharged home or you mean?

I: Yeah or when they are getting better.

P: When they are getting better?

I: Do you give special care still?

P: Oh we still do. We give the special case…Sometimes like they’re saying if a child is on maybe CPAP and he improves then we put on normal oxygen so if ehm that is if respiration is so bad but if not child is put off. But then if we consider like that um when baby’s cold he has other conditions that might trigger this condition again if it’s prone to being cold we put baby in an incubator and we will make sure that we wash our hands well before attending to baby. So ehm the prescribe medications too are given as…the medications are given as prescribed too. Those are some of the special things we do.

I: And what about um like special care for when they’re discharged?

P: Special care when they’re discharged. When they are discharged we have eh public health nurse on the ward who do a follow up and they also they are given dates to come for review so then one continues the with the public health nurse and the doctors and nurses who’ve been seen at clinic as they come. So that what is done there.

I: Ok, are mothers typically given special instructions for caring for babies that lived uh but you thought they were going to die?

P: Yeah, we we give them hmm…Whilst mothers are on the ward, we educate [cutout-6:32] also discharge, education is given to mothers as to how to handle babies. And even amongst ourselves as staffs too, we are educated and being taught how to handle baby. And in cases where we have any difficulty, we ask our seniors what to do. Like what is the next step. They tell us and we do.

I: Um, do you feel like uh mothers usually understand the instructions?

P: Uhh, mothers understand based on I think the educational background…and also age. Sometimes age comes in. Extremities of age, those who at um too old or too young. Yeah, the level of education. So some do understand well but some too, I think. So sometimes when we see that, we invite other relatives. We ask the person, especially with the teenagers, when you know the person’s level you can tell that this one oh she might not be able to understand everything so we invite in a second person who will help…who will help her whilst she’s at home or whilst taking care of baby. That’s what we do.

I: So, for the moms that don’t follow the instructions, what is usually the reason why they don’t?

P: (pause) Hm, moms who don’t follow instructions, and that’s what I’m saying that some is because, pardon?

I: You want me to put that right here? (Referring to books she is holding)

P: Oh ok. As we are saying is it’s the understanding. Some don’t understand but then they might not ask any question. But in our setting it’s very common. They or somebody would not understand something and the person would not ask for explanation so sometimes too you ask the person to perform or do something then you know [cutout-8:53]. So all these things I said, maybe you didn’t understand and you could not ask me so maybe because information was not maybe broken down to their level. Sometimes you are so busy, have to break down every little information, we are not able to. We assume maybe the person has understood but it will, it’s also because they don’t ask questions because when you are telling the person something and he doesn’t ask you anything, you assume he’s understood everything so.

I: Do you feel like um there are any cultural barriers to um the mothers doing the instructions?

P: Oh ok. Yeah, that one too mhm. It’s there, cultural beliefs. There are some things when you tell them and they go back home. This place where you give birth, mostly mothers come in, grandmothers come in and the knowledge they have, also they want to apply that one. So I think that one also have an influence in it. When the person goes, and especially if the mothers and the grandmothers didn’t hear directly from the health worker, and maybe the mom goes home and she’s like, “Oh this is what the nurse told me.” She will be like, “No, maybe I give birth to you, I took care of you, I did this for you, it worked out so we are going to do the same thing for the baby.” So that one also has an influence.

I: Have you ever discussed uh one of these cases of babies who survive when you thought they would have died with your supervisor or a co-worker?

P: Yes, I have. That one, I, it was even just just yesterday, we had one case like that. Like the baby I was telling you about, it’s an asphyxia baby, and we bagged for about 30 minutes but whenever you stop, the baby stops breathing, when you stop bagging—he was intubated and we were bagging with oxygen. But when you stop bagging, baby would stop breathing, so it got to a time they had to leave baby. So even the doctor came in, did everything. At that time pupils looked dilated, baby was seized breathing, but before they would start certifying death, the baby started breathing on his own again. So even that, yesterday I was passing by and I saw that I was in another cubicle but I saw baby’s chest moving and I went in to tell my colleague that “Aye see this baby, this the wonder baby. Baby has come back he’s breathing.” So were thinking that oh maybe for sometime it was, but from that time baby started breathing and we we were all sat down to discuss. So the doctors went further they were saying “Ah does baby have liver at all, whose baby is it?” They checked and everything was fine so we left baby and they uh, so baby’s alive so we have been discussing about it, we did.

I: And so are cases like this commonly discussed amongst the team?

P: [cutout-12:21] discuss them as a team, yes we do.

I: It’s common to discuss it?

P: It’s common, yeah, because um it’s very surprising. Sometimes you have done your part you think even baby is gone and so when it happens, this one we normally discuss it as a team. We are like what happened, we want to know more, that what could cause this so maybe so that in the next or subsequent ones we will be careful so that we don’t just certify quickly and go and put baby in [inaudible-12:52] whereas baby is not gone, so we do this, that.

I: Ok, um…if so when you discuss these cases what is usually the outcome of the discussion?

P: And that’s what I was saying, and the outcome is that we should like sometimes we should take time, yeah before um we declare baby dead, baby dead because it it might be seem that everything might show alright that baby’s gone but then. So that is what we learned from it that, sometimes we just have to take time. So sometimes once so when deaths are even certified we leave the baby there for some time yeah before we take to the morgue.

I: Mhm ok. Have you ever received formal training on how to handle these cases of babies that survive when you thought they should’ve died?

P: You said any formal training?

I: Mhmm.

P: No No.

I: No?

P: Yeah, is just our general what we know, but not any specialized care in that area.

I: Mhmm, do you think there should be more training on how to handle um these cases?

P: Yeah, there should be more.

I: Mhmm.

P: Because um we are in the intensive unit already an intensive unit but then like those cases they are also special cases in the intensive care unit so I think we will need more. Yeah education like that so that we know how to handle properly.

I: What kind of training do you think would be helpful?

P: What kind of training? Mm the training like their saying as to how to take care of them after survival; what we can do more to help them yeah so that even after taking care of them here it’s that one they go home maybe we lose them. Because like I’m saying when they come for review or follow up when we discharge sometimes we are not able to follow up, it’s the public health nurse or when they come for review so we don’t know what normally happens when they go home and how to care for them um when they are fine. We will know, we will also know what to tell mothers so when they go home they can take proper care of them.

I: Ok, what do you believe are the most important things to understand in order to handle these kinds of cases?

P: …Ok, to handle these kinds of cases. Uh we should know what is going on. We should know the cause like what what would lead to this. But if we know we are taught the causes what brings about this, then we can know how to prevent it yeah. So we knowing brings this and that we being taught that it it’s something that happens. It can happen because of this, that, that. Then we can also know how to prevent we should be taught how to prevent it.

I: Ok, are you familiar with the term near miss?

P: Near miss, you say am I familiar with it?

I: Hmm?

P: You are asking me if I am familiar with the term near miss? No no.

I: Ok, um so a near miss is uh what we’ve been talking about, when a baby looks like it, you would think like oh I don’t think this baby is going to make it but they do so we nearly missed them.

P: Mhmm.

I: Um, do you think healthcare workers all have the same idea of what a near miss is?

P: No, I don’t think so. I don’t think everybody does. Mm.

I: Ok, so healthcare workers may not know the word near miss, but do you think that healthcare workers in the NICU see like oh this baby is ill and then this baby is very ill but they still are making it and they, you know, they make a distinction between those two babies?

P: I don’t get it, can you eh huh

I: Do you think that healthcare workers in the NICU um make a distinction between babies who are ill and babies who looked very ill and almost died but survive? You think they separate them or its just all babies, all of these babies look ill.

P: Oh we separate them, yeah. We separate them.

I: Do you think its useful to separate them?

P: Yes, it is. It’s useful to separate them so that [cutout-18:09] mentioned earlier on it’s an intensive care. That means every baby there needs an intensive care but then if we are able to separate them, those ones who have extra care so we we do. A place for instance, the first cubicle, is for very very ill patients. That’s where we keep them. When we see those ones we know that mhmm this child might, that any moment from now they are kept in the first cubicle area, yeah. So we we do separate them.

I: Um, if you knew a baby was classified as having a near miss, do you think it would change how you managed that baby?

P: Mhmm yes, it will. Because, sometimes you you think we think that oh as for this baby (sucks teeth) not likely he will make it. So you when you are even doing so much you you even feel down that (sigh) after all I’m doing maybe I’ll I’ll definitely miss baby but then if we have them at the back of our mind that there is a near miss, those baby you might be clear that um this one will go but it’s like there’s a chance of survival. Then you you put in more and be hopeful with what you are doing. All your interventions, you know that it will work or it might work.

I: What challenges do you think babies who experienced a near miss will face as they age?

P: Babies who experienced a near miss. Um that is if maybe their condition if there was still something that was not well treated. That lead to they being classified as a near miss and maybe they just survived by chance and there’s more to be treated—concerning their condition—which was not dis-ehm uhh which would not be de-eh diagnosed then I think the near future it might becoming up and it will effect them. Other conditions might come up so

I: Ok. Do you feel like the healthcare system is prepared to handle um their needs like when other conditions come up later as their older?

P: Yes, there is. Or maybe not enough but then there are some yeah measures in place to handle but not it might not be enough [cutout-21:03]. There are some measures yeah put in place, so that’s why they come for follow up or reviews, so that in case anything comes up. Because it’s not likely you you will be able to see everything or diagnose everything. But like we are saying some, with time, will be come showing up. So as they come for review we follow up we are able to do that yeah. But mhmm it might not be enough of what we need to take care of those things, it might not be enough.

I: And so, why do you say there’s not enough? Like, what do you mean by that?

P: Mmm, umm, hmm…even that one starts from the ward once they’re even on admission. Like I was saying, there’s some equipment and even um some equipment gadgets we have to get on the ward which will aid in the care of the patient and even from the start we don’t have all those things done. So that’s why I’m able to uh uh I say that maybe with time even what they develop…We might not have everything to take care of that mhmm.

I: Ok, um do you have any other comments about babies that experience a near miss that you think is important for like us that are doing this research study to understand?

P: Mmm…no…but what I have is… We should I think we should just have enough training for staffs. And also we should have the proper (/training/) because it’s one thing you being trained or we being trained and as we are being trained that is more the theory side. We learn more of the theory and even practicals might happen that when you even go to school, sorry. When you even go to school you get the equipment, you get to see everything there. But then when you come on the field we don’t see those things. So you might have the knowledge but implementation might be difficult because you don’t have those things to work with. You know what to do alright but then the equipment. So it’s all about most of our problems has to do with our equipment, lack of equipment and gadgets, yeah. So after training we still need the things with the uh equipment so that we can do proper implementation.

I: Ok, well thank you for your time and for answering the question [cutout-23:57] Will help us understand more about why babies that seemed like they were going to die, live instead. Uh do you have any questions?

P: Umm…no I don’t.

I: Ok, um so if you have any questions in the future you can contact Dr.\_\_\_\_\_\_\_ and you can also ask him for my contact information if you wanna ask me any questions. Um so that is it.

P: Ok.

END OF INTERVIEW

Type: HCP Interview-CC9016

Date: 21-7-2015

Position: Doctor-Senior Specialist

I: Alright, thank you for taking the time out of your schedule to meet with me today. As you may know, this project is focused on learning more about babies who have life threatening complications during and after delivery, but who survive. Your thoughts and opinions about why some babies survive while others die are very important to helping us understand these issues better. As a reminder, I will be recording our interview. This is just so that I have something to help me remember what we talk about. It also means that I won’t need to take a lot of notes, I will just write down what I would like to follow-up on. Just so you know, the recordings will never be played publicly. We will transcribe them and then destroy the tapes. If there is anything you don’t want to talk about, please let me know. Also, we can stop the interview at any time. Please let me know if you would like to stop. What we talk about will remain confidential. I won’t share the details with patients or others at the hospital. You will not be named in anything that is written about this research. Also just so it is noted on the tape, this is interview CC9016. We would like to learn more about your experiences with babies who are ill and their outcomes. You’ve been working on this NICU for \_\_\_ years now and some of the babies have had severe complications. Some of them, you may have struggled with and they died. Some of them, you may have struggled with and they lived. Some died no matter what you did. Some lived when you thought that they were going to die. What do you think was the difference between those who lived and those who died?

P: (laughs) This is a tough one. Um…a lot of the time it’s at the time, it depends on the time that they came, the time that they are seen. If they are seen earlier, an intervention can be put in place. And if the right intervention is put in place I mean they survive. And sometimes they come and maybe the intervention is not the right one which is carried out and so maybe depending on the expertise of the person or whatever the baby doesn’t make it. Um sometimes too the intervention is delayed so it’s it’s not done at the time when it should be done so it is delayed. Uh basically I think these uh things cause some to survive, some to die.

I: Mhmm, what would you say is usually the reason an intervention is delayed?

P: Uh…maybe maybe the lack of expertise of the person dealing with the um…Sometimes too maybe that what should be done is not available. So we are not able to do it. In settings and like cases of like asphyxias and so on they come and sometimes they are you try to manually resuscitate them, you keep on having to bag and mask, bag and mask ventilate them and able to continue that for forever. And so of them decide, people get tired and people stop ventilating, yeah.

I: Ok, can you tell me about your experiences with those babies who lived when you thought that they were going to die? What diseases or conditions did these babies have?

P: Um, some of them uh what readily comes to mind is some of our kernicterus babies

I: Hmm? [/what?/]

P: Kernicterus, they come with severe jaundice, severe neonatal jaundice. And ehm you think they are actually that bad and they are going to die the next moment and some of them survive but a lot of them have uh end up getting cerebral palsy, yeah. Um one or two cases actually again, I mean with those who are asphyxiated, they come keep on eh maybe with a good heart rate, you ambu bag, keep assisting their respiration as much as you can. And then it get to a time we we are human, you get tired. And you will just leave them on oxygen and after some time they just pick up by themselves. We haven’t been able to ascribe one particular one that we had recently, we haven’t been able to say exactly what happened and why the child survived. At least we were given the oxygen if the child would breathe on its own that fine but we were not actively assisting respiration. Ehm so I don’t know.

I: Mhmm, yeah so I mean I know so like you said it’s hard to say like why some end up living but if you had to come up with a reason for any of the cases you’ve seen on like why in an instance you thought some of theses babies are living versus others?

P: Hm [long pause]. Um…it’s hard to say, it’s hard to say.

I: Ok, um what so is any special care given after the diseases or conditions are resolved?

P: Any special care is given, uh well…yes I mean if they do survive. We want to make sure we follow them up as closely as possible. So we follow them up. We don’t have a big place so we don’t tend to keep babies for long periods of time. So what we do is we will let them go and rather do early follow ups. So if other babies would get maybe two week or a week’s follow up, I mean they maybe three days or at most a week. We want to see them for follow up.

I: Mhmm, are mothers typically given special instructions for caring for babies that lived but you thought were going to die?

P: Um, yeah, they are given, most of the time it’s done by the nurses, yeah. We would write instructions as to what to give and what to tell the mothers, etc. Yes, it’s given.

I: Mhmm, and do you feel like mothers typically understand those instructions?

P: Hmm (laughs) that’s another thing because sometimes I mean you are out and your nurses why wouldn’t you tell the mother this, why didn’t you tell the mother that. And they tell you that we told the mother, we explained to her and sometimes they do understand but then there’s a lot of pressure too from like people at home.

I: Mhmm.

P: Maybe their mothers or their mothers-in-law and people elderly women who are helping to to take care of the baby so maybe you, they are not able to accept what was told to them in the hospital so they have to do their own thing at home. So yes maybe I think they understand but then there’s a pressure on them from other fac—other areas areas as well. To disregard what is told from us and do what they want to do at home.

I: Mhmm, and so well I know you mentioned like like you said the pressures at home but when, besides that, when mothers don’t follow the instructions what are usually the reasons why? So it could be that but if you think there is a more a different reason why, what would it be?

P: Why they don’t follow the instructions?

I: Mhmm, like if they if there’s mothers that don’t, why don’t they follow?

P: Uh maybe they didn’t understand, maybe they didn’t understand what was told to them. Or it was too much hustle. For example, you’re to um feed your baby every two hours and eh you don’t have much help assistance at home it might be too much stress on the mother but the the mother will not follow through with instruction. So uh yeah so maybe they didn’t understand, it was too much stress to do what they were actually asked to do. Sometimes too if it requires money, I mean when it comes to mixing of milk, what volumes to use and that kind of things. They might want to dilute it a little bit more so that it will stretch a little longer so…

I: Mhmm.

P: Yeah.

I: Mhmm, uh are there cultural barriers to the mothers like following the instructions?

P: Uh yeah there are a lot of cultural things that are done like babies are kept in the dark. They are not eh some places I mean there is an evil eyes will see them so they don’t even look at the babies faces to notice that they are jaundiced until about a week later. And by the time they notice, their jaundice I mean it’s gone beyond what could be salvaged. Yeah so that’s one common thing that babies are not brought out to the open early. Uh yeah and a few places too eh the way they treat the cord. Some will use a hot stone, its not that common but occasionally a few to make it fall off.

I: Mhmm

P: So they put a stone hot, fire or something like that onto the cord so that the cord will fall off early. Um and then um I don’t think eh there’s applications, herbal applications of cord. (sucks teeth) I don’t think it’s that common, well I haven’t come across many of them. But these are the common ones that really…

I: So what do you feel like can be done about the cultural barriers that exist so that mothers can follow instructions?

P: Hmm, it’s more of education, I mean it’s more of education. So uh maybe meeting the mothers or I mean you know there are many social groups, especially here most of them are religious groups. So I think it’s more of advocacy education using those groups to educate mothers so that they do also go tell their sisters and friends and so on about what to do. So a lot of, some church programs advocate and uh a few incorporate these kind of education and health education a bit into it. So that’s what they do.

I: Have you ever discussed one of these cases of babies that survived when you thought they would’ve died with your supervisor or a co-worker?

P: Um we’ve discussed but not into too much detail.

I: Mhmm.

P: Yeah, I mean there was one that like the one I recently talked about. We’d all thought that baby would eventually die and I think he went home, he went home, so. And again sometimes you are limited, I mean you don’t have yes you know something is but you are limited when it comes to investigations so you ah you work in the dark more or less, yeah. So yes we do discuss it but not to a conclusive end I would say.

I: Mhmm, so what would you say is usually the outcome of the discussion?

P: Um, maybe inconclusive. Inconclusive I’d say.

I: Mhmm, ok. Um, have you ever received formal training on how to these cases of babies that survived when you thought they would’ve died?

P: No.

I: No, ok. Do you think there should be more training on how to handle these cases?

P: Ehhh yeah.

I: Mhmm, like what kind of training?

P: …What kind of training, eh…maybe what to look out for if there were any predisposing factors that could let you know that this would happen so you are not taking on hours. And um… yeah that’s what really comes to mind.

I: Ok, so in general, what do you believe is the most important thing to understand in order to handle these kinds of cases?

P: I think if there are predisposing factors

I: Mhmm.

P: that could give you clues that to pay more attention to this baby and this baby is not really a regular baby and may not follow the typical signs. I think those are things that they should help.

I: Mhmm, ok. Uh what do you believe is the most important things for mothers to understand in general when you’re discharging these babies that almost died?

P: Um, that they if it’s something that was preventable. I mean for them to be sure um to be careful not to make it happen again. And I just remember one other baby that I mean actually not in this hospital but I was in \_\_\_\_\_\_\_ before I came here. It was a preterm that I think was was was about to be discharged and then the nurse noticed the preterm had stopped breathing and so quickly rushed uh the baby and we had to resuscitate again and assist in breathing and give uh drugs to help with respiration and so on. But this child has made it and child has is growing well now I think 8 years now or something, is he’s normal. But I think it was the mother was feeding and eh and the baby aspirated at the time yeah. So I think so if such a mother understands the need to take more to have more patience when you feeding the baby I believe you need to let them understand. Let them appreciate the significance of what they can do to prevent such near misses from occurring, yeah.

I: Ok. Are you familiar with the term near miss?

P: Near miss, yeah a baby that um almost died, that you expected to die but didn’t die.

I: Right.

P: Ok.

I: Do you think healthcare workers all have the same idea of what a near miss is?

P: I don’t think so.

I: Mhmm.

P: I don’t think so. I think some may have but I don’t think it’s all healthcare workers and healthcare workers is a whole spectrum. Yeah so I don’t think everybody understands what a near miss is.

I: Why do you feel like well why do you think its not a commonly known term?

P: I don’t think we emphasize it a lot. I don’t think we…capture such cases as giving that term.

I: Mhmm.

P: That designation I wouldn’t [inaudible-16:12] but I don’t think we make that classification that uh I don’t give them that identity of near miss.

I: Mhmm, do you think it’s a distinction that is useful to you as a healthcare worker?

P: Oh yeah, yeah. Because I think it will make you keep an eye and whatever the reason for that near miss occurring, you try to em educate the mother or if it’s a healthcare worker or whatever that caused that near miss so that eh that is prevented next uh another time around.

I: Mhmm, so you, so if you knew that a baby was classified as having a near miss, do you think it would change how you managed that baby?

P: Yeah, yeah, yeah. Because I wouldn’t want what happened to happen again.

I: Mhmm, right, ok. What challenges do you think that babies who experienced a near miss will face as they age?

P: (pause) I think it depends on what caused a near miss. I mean what the near miss is.

I: Mhmm

P: Uh so I think some may not face any challenges. But some may because uh there maybe complications as a result of the event that occurred

I: Mhmm.

P: So I think it it depends.

I: Mhmm, do you feel like the healthcare system is prepared to respond to the needs these babies that have further complications down the road, do you think the healthcare system will be able to respond to that?

P: Hmm (laughs)…um…hmm I don’t think so (laughs). I don’t think so because there that a lot of babies who have various complications. And then the systems, well systems are now being generally um set up to take care of them. And that leaves like those who have complications whatever complications whether it was a near miss or whatever it was, would be part of those with general complications. And our system is not, I don’t think we are we are ready to respond to it, unfortunately.

I: Mkay. What so what do you believe is needed to increase the numbers the number of babies who survive?

P: I think it’s more of training and um…there may be need for ah you know the system too is such, like I tell you that there’re the things which maybe you needed which maybe are not available. And if people are constantly…frustrated at a point eh it it gives a kind of attitude.

I: Mhmm.

P: So that people are not willing to make an extra effort. So maybe you are you’ve seen to many of them, you know the outcome, you know how it’s going to end up so why make the extra effort if it’s eventually going to end up that way. So I think it it would be for…yes you need to educate mothers and so on if there is something they can do to prevent such near misses. But then also more of health workers as well need to be educated. And then um the needs of the system should be attended to, like and then further training as well of the health health workers. And because like if it’s a ventilator that is needed, the ventilator is not available and you need to bag bag bag. You get some point tired and you can’t continue for 48 hours, you can’t, there’s a time you have to…

I: Mhmm.

P: So, I mean those are the basic things that need to be provided and then further training and then education of mothers.

I: Mhmm.

P: And basically that’s it.

I: Ok, what do you believe is needed to make sure these babies that have had a near miss like live long term?

P: …Hmm…I mean the system does address any complications that they’ve come up with.

I: Mhmm.

P: Mmm. The system yeah.

I: Ok, so do you have do you have any other comments about near miss and treating babies that have had a near miss or anything about near miss in general that you think is important for us to understand for this study?

P: …

I: Maybe something we might have not covered.

P: Mhmm…mmm…well what I mentioned earlier that I mean like the near misses sometimes they come up well with no complications but a lot of them I mean have complications further down the line and um… And its there’s more of like putting structure into the system, putting systems into place that will help address complications that generally arise. May not be near miss, may have been expected but still has a complication of one sort or the other. So I think it’s more of a system to address complications that may arise as a result of treatment interventions that may have been given late or may not have been given at the right time. That’s what that’s what comes to mind.

I: Ok, well again thank you for your time and for answering our questions. We hope your answers will help us understand more about why babies that seemed as though they would’ve died, live instead. Please let me know if you have any questions.

P: Mmm, no.

I: Ok, if you have any questions in the future I can be reached through \_\_\_\_\_, you can also ask her question directly as well.

P: Ok.

I: So…

END OF INTERVIEW

Type: HCP Interview-KA9009

Date: 30-6-2015

Position: Nurse

I: Ok, um so thank you for taking the time out of your schedule to meet with me. Um, as you probably know, this project is focused on learning more about babies who have life threatening complications during and after delivery, but who survive. Your thoughts and opinions about why some babies survive while others die are very important to helping us understand these issues better. As a reminder, I will be recording the interview. This is just so I have something to help me remember what we talk about. It also means I wont have to take a lot of notes, just stuff I need to follow up on. Uh, just so you know, the recordings will never be played in public. We will transcribe them and then destroy the tapes. If there is anything that you don’t want to talk about, please let me know. Also, we can stop the interview at any time. Please let me know if you would like to stop. What we talk about will remain confidential. I won’t share the details with patients or others at the hospital. You will not be named in anything that is written about this research. And just so the tape knows this is interview KA9009.

P: Ok.

I: Ok. We would like to learn more about your experiences with babies who are ill and their outcomes. You’ve been working on the NICU for over \_\_\_ years some now. Some of the babies had severe complications. Some of them, you may have struggled with and they died. Some of them, you may have struggled with and they lived. Some died no matter what you did. Uh some lived when you thought that they were going to die.

P: Yes.

I: What do you think was the difference between those who lived and those who died?

P: Thank you. Ok, yeah those who lived, I know its uh it was difficult for us on some occasions. We struggle for them to survive because here we deal with babies with a lot of complications. Babies with problems. Generally, babies with problems. Here we admit babies from the northern sector and the middle belt of the country. So we get a lot of complicated conditions, yes and with our effort though we have a lot of challenges here, we do well to let these babies live. And, um, we are proud that we we we’ve with our effort a lot of babies have lived. Though some die which, as you’ve already said, some are avoidable, some you cant do anything to it. Some, those who are avoidable are mostly those who delay from the referral centers. Some also go to seek, eh, help I mean health for their babies at various places apart from health institutions. Some go to herbalists, some go to prayer centers. Before they bring their babies here, the condition is bad, so no matter what you try to do, the babies die. Some of also out of ignorance they do certain things to their babies, which the literal when people advise them to bring them to the hospital as I’ve already said the condition is already out of hand, you cant do anything to it. Some also we think, “oh as for this baby oh there’s nothing to be done oh (sucks teeth) alright, ah lets try our best if she can live.” I quite remember we had a baby about five years ago who was 0.7 (/kilograms/), the mother apparently aborted her and just abandoned the baby and somebody took the baby, put the baby in an ambulance, drove far away for about two hours journey to this place. We were able to nurse this baby gradually, little by little, this baby survived. We the nurses were doing kangaroo mother care for this baby and to our amazing, I mean the baby survived and he was given for adoption. This baby when he was leaving this ward was weighing 0.9 (/kilograms/) that’s 900 grams, and we were so happy. We even named the baby Beauty, because we thought oh this baby, nothing could be done but what we were able to make this baby survive. And we see a lot of babies that we have with our effort, though we don’t have a lot of gadgets to take care of these babies, the little that we have, we make use of them, and these babies survive. We have a whole lot of them where they come they come back with their babies to show them to us and we feel proud and satisfied with what we have done, yes, yeah.

I: Ok. Um, can you tell me about your experiences with those babies who lived when you thought they were going to die? Which diseases or conditions did these babies have?

P: Yeah, as I’ve already said about this premature baby. Very low birth weight and premature baby, that was her problem. She was an extremely preterm baby. And we had a baby who was very asphyxiated, severe asphyxiated baby. And this baby we lost hope but finally he survived, though we, we know the baby will have some problems as he grows cause of the severely asphyxiated form he was referred into this unit. Ah after the baby was six months, the mother brought the baby here, yeah. He was, the mother was finally difficult I mean the baby was difficult to sit and maybe you to hold the head, I mean but the baby, the mother was, we encouraged the mother to continue with whatever eh she suppose to do for the baby. While we haven’t heard from her after some time but we know the baby is still alive. As to whether the baby’s eh milestone is within the normal or we know it wouldn’t be within the normal like the other normal babies but we know that the baby is still alive. The mothers continue bringing their babies, we, I quite remember we had another baby with some eh abnormality, cleft palate, it was a condition called Patau’s. And this baby we thought “oh, it wont survive” but baby survived up to a level but we, we later on got the information that baby had died. We have a whole lot of babies who they (phone rings 7:17- 7:45) the mothers bring to show us that oh this baby survived after all these things. We had a baby who had um, a whole lot, there are many, there are many. I can’t remember most of them, but I know we have a lot of babies who have survived out of eh severe conditions, yeah.

I: And why do you think they survive and other babies don’t, like if you had to say a general reason?

P: Yes, eh it depended on most of the time the mothers. They had confidence, we we usually give them health talk every morning, give them health talk. Most mothers have confidence and they also have the they have confidence in us. Cause they know ‘oh, I know the nurses can do it’ I remember one baby also who was 0.8 (/kg/) the mother asked me “(8:22)“do you think this baby will survive?” it was a midwife, “do you think this baby will survive?” I said “well, its all in the hands of the Lord, eh somebody’s life is not in our hands, human being alive is in the Lord so we should all pray and have confidence” low and behold this baby survived. 0.8 (/kg/) the child is now three years old, yes. The mother is a midwife so whenever she comes to \_\_\_\_\_\_, she wants to bring the baby show it, the baby to us, “\_\_\_\_\_\_, have you seen your pretty boy, he’s now in the nursery.” I mean we feel satisfied that at least we have done something. And eh the survival rate as I’ve already said depended on eh the nurses here, the mother, and also ehm I mean money, money matters. Yes, because if you don’t have money and a drug is prescribed for you, you don’t have money to buy definitely the baby, eh most of the drugs in this hospital are not insured. Even though we have insurance for drugs but the not insured ones are the expensive ones. So if the mother hasn’t got the money, its difficult for her to eh get that drug. I remember we had a baby who was referred from [inaudible-9:51, city/town in Ghana] with a condition called [inaudible-9:55] syndrome, has an [inaudible-9:58] where the abdomen, abdominal content are protruded like an omphalocele. And the mother was a teenager, so the grandmother was taking care of this child and getting money to buy drugs was difficult. So we the nurses and doctors were contributing because we all felt I mean sad for the situation that the mother had gone through because he had had a series of blood transfusions because eh I understand she bled a lot during the delivery. The baby, the woman didn’t deliver here, she was referred from outskirt. But with the help of nurses and doctors contributing buying drug, a drug which was it wasn’t so expensive but the parents couldn’t afford. We were able to let this baby live. This baby lived to our I mean we were all amazed. Wow this baby, I mean even the doctor in charge when we she saw the baby for the first time, said “ah this baby he look like an old man, very tiny, wrinkles here and there” but when we got this drug for this baby oh, he just started growing. This baby survived and we discharged the baby without the parents paying anything. We contacted the social welfare people because when we listen to the history, the background of the parents, they couldn’t pay the bill because this child spent almost six weeks on this ward. And the bills was so much so we gave her problem to the social welfare people where they also took up the problem. And we allowed the child to go with the grandmother, the grandmother was taking care of this child so that that the grandmother have even named this child after me. Yeah because she said it was my effort and eh the other doctors effort this child has survived. So we are really happy a lot of mothers a lot of mothers, as you’ve asked, where we were thinking that they’re babies would died but they survive. We have a lot of them which we are proud of, very very, yes

I: Ok, um is any other special care given after the disease or condition is resolved?

P: Um (background noise), as you asked, depending on the problem that the child brought, usually after they they’ve been discharged they come on reviews and the doctors usually refer them to eh conditions like asphyxiated babies, they refer them to the neuro clinics those with other abnormalities because we have subspecialties in the the unit, you know in the department. They are referred to these specialties where they continue their treatment, yes.

I: Ok. Are mothers um usually given special instructions for caring for their babies if they lived when they looked like they were going to die?

P: Um, yes to some extent. Because you can’t nurse a baby without the mother. Most of the time we give special instructions to them, yeah. As we nurse them alongside the ward. But when they are able, when they are they are able to live and they are going home, we still want to know how the mothers are taking care of them, so we usually let them come to the ward on alternate days just to have a look at how the babies are faring, up to a certain age where we think “oh this baby is ok for the mother to take care alone” until we discharge them completely. Other than that, we allow them to come on reviews either every other day, especially if preterm babies or every week for us to follow their care. Because we can’t go to their homes, we allow them to come. We follow their progress as they go until we are satisfied that oh now this mother can take care of the baby without our help, yeah, we do a lot of that.

I: Ok, do you feel like the mothers usually understand the instructions?

P: Some do understand, others don’t. Those who don’t are those who when they go home, they listen to their the old ladies tales hear and they “oh when my baby had this, this what I use” or “when my friends babies’ had this is what I use” those who listen to their home as we call them the home doctors and nurses. Those who listen to them, usually come back with other problems or their baby’s condition deteriorate or yeah. But those who listen our advice, their babies thrive very well, yeah.

I: So, besides that, when mothers usually don’t follow the directions what is the another what are the other reasons why they don’t?

P: Um, mommy, it’s a big problem to some parents, yeah. Cause maybe you are, you advise the mother to lets say the mother is not having enough breast milk and you allow the mother to let’s say add formula to it. (gestures if she should turn fan on)

I: Oh no, its fine.

P: A mother may not be able to buy. Lets say the child, the child can eat a tin of formula lets say four days. But because she hasn’t got enough money she will buy the tin alright but the child will use it for a week

I: Mhmm

P: Instead of her mixing it at the right quantity, the right water. She will take a little of it, mix it then eventually the child will get diarrhea and she will bring the child back. Because she hasn’t got money to buy this formula every four days. Meanwhile that is the instruction we have given her, as she’s leaving the ward. “Madam when you go, mix this milk this way” but when she goes home you are not with her at home so she will be sad “oh I will use this milk for one week.” And the way it is prepared we teach them on the ward. When they go home, she may do it differently then the child turns out to have infections and come back yeah. So some of them because of financial problems, their babies get worse and they come back, yeah. Those who are able to do I mean follow the instructions, their babies thrive well, yeah.

I: Ok, do you feel like there are any cultural barriers to the mothers understanding the instructions for their babies?

P: Um, yes. Some have a lot of cultural beliefs, they have beliefs. Um oh as for our tribe this is how we do it, as for our religion, this is how we do it. So you will be trying to give the direction un huh give an instruction to a towards a particular direction, she will also because her belief do differently. For instance we have a religion in eh a religion who don’t eh I mean who don’t take blood transfusion, yeah. So if the child is anemic and you want to transfuse the baby, they will say no, in our church or our religion we don’t do that. She the person will insist but here at least we have the courts backing that a child below 18 years it everything that has to be done for the child the courts have backing for us so we can transfuse the child, whether the parents admit to it, I mean they want it or not. We have to talk to them initially, try to explain thing to them, if still they don’t want it, we we go for court order. Then we transfuse the child to save the child’s life, yes. But still when they go home, they have other beliefs, yeah they have other beliefs cause of different religions and tribes, yeah. For instance, theres a tribe where a baby or a child is not given eggs to eat, they belief if you give eggs to a child, the child when he grows or she grows up she will become a thief. That’s their belief, I don’t know how it, yeah. So a child, a baby from here maybe growing well, when she, the child gets to a stage where he needs to take all these proteins, they will not give it to them. So when the babies become, they fail to thrive, they come emaciated, they come back to the hospitals.

I: Ok, have you ever discussed on of these cases of babies that survived when you thought they would’ve died with your supervisor or with a coworker?

P: Uh, yes we do we do discuss amongst ourselves “ah this baby, we all thought this baby was going to die.” An example is this preterm baby and the baby with [inaudible-20:41] syndrome, we all thought this babies were going to die but they survived, yeah. With our little effort,

I: Mhmm

P: our little effort, these babies survived.

I: Mhmm…(P says she will turn on fan) ok (laughs) (pause while she turns on fan) Um usually when you discuss these cases, what is the outcome of the discussion?

P: Yeah, among ourselves we we feel satisfied that we able to do something for this child to survive, yes. And if and yeah, in our unit yeah we don’t spread outside or even if you go talk about it we don’t mention names. Oh even this case we had similar ones sometime ago we were able to do this. So most of the time it is kept in the unit, don’t spread news outside. But within ourselves here we feel proud and satisfied that we are able to let this baby, who we thought would die, survive, yes.

I: Ok, have you ever received formal training on how to handle these cases of babies that survive when you thought they would die?

P: Um, not really, I haven’t any formal training on such babies. But um um I trained, I’m a pediatric nurse I’ve been trained as a pediatric nurse, general child nurse, yeah. But haven’t been trained on these particular babies, those who you thought were going to die and they have survived, no. I haven’t had training on that.

I: Do you think there should be uh training on how to handle these kinds of cases?

P: Yes, yes. I would love to have training, myself and my colleagues. Even if we have um a short course, let say one month, three months, short courses on how to care for these babies who we thought were going to die and survive. I would be happy.

I: Mhmm

P: Yes

I: Is there any other, is there any specific kind of training you think would be useful?

P: Uh, actually nursing neonates, ideally all nurses who are nursing neonates should have neonatal nursing. All those nurses you see on the ward apart from………., all of them haven’t had any training on child nursing or neonatal care. Its all experience on the ward. We only experiences on the ward, that has kept. Me for instance, because I’ve nursed neonates for a long time I when I had the opportunity to do the pediatric nursing. I have wanted to do the neonatal care, unfortunately when I got there, there wasn’t, the program was there alright but I couldn’t get any other person who wanted to do that program, they didn’t have a lecturer for me, so I had to do the normal child pathway, yeah. So its very necessary, I think its very necessary for nurses working in the NICU to have neonatal nursing, yeah. Its better that way that eh when we get that training it will improve our skills better. When we are doing our best, it will improve our skills.

I: Ok. Uh what do you believe is the most important thing uh to understand in order to handle these cases, just in general?

P: Uh, yes, um if you are a nurse working in the NICU, you must have your mind that any baby who comes to NICU has a problem. Needs emergency care, or needs emergency or skilled hand to take care of this child, yes. So um we take every baby in NICU here as a special baby who needs special attention. Because if the child hasn’t got any problem, it would have been with the mother [inaudible-25:48]. But the surprise when the baby comes to NICU, it needs a special care. So we always have that in mind, that any baby coming here is an emergency case. So we don’t, I mean, we don’t, eh, drag our feet on them. So that the baby can take care of them. Whatever we have to do before even the doctor comes in, the nurses we do.

I: Ok. Uh, what do you think is most important for the moms to understand before they go home if they have a baby that almost died but it lives.

P: Yeah, we rarely tell these mothers that because this child we thought was going to die but has survived and you can a very special child. Oh all the babies here are special, they are unique. But these particular ones are special babies to us. So whatever they see in them as soon as they go home, whatever difference you see or whatever they see in their baby and they, they don’t understand or they don’t know if they should bring the baby back to the ward at least we will know what’s happening to the baby and we take up immediately, concerning the care. We we we talk to the mothers, [inaudible-27:15] when they are leaving the ward we educate them. See this baby, you and I thought the baby was going to die. But you see the baby has survived so whatever problem you see in this baby, bring the baby back so that you have continued care.

I: Ok. Are you familiar with the term near-miss?

P: Uh, yes. Near-miss. I, I, yeah. I usually hear it [inaudible- 27:50]. Near-miss is, to me, I understand that, uh, would be a baby who we had like the same. Like we had thought was going to die or we had neglected, in quotes, not neglected per say but we thought, oh, baby you don’t have to waste your time on this baby. But then something will happen and the baby will survive. Yes. That’s how I understand near-miss. We nearly lost this baby.

I: Yes.

P: But she has survived. Yes. That’s my understanding of near-miss.

I: Yes, that is. Yes, like you said, it’s when a baby we thought would not survive but they survive. Do you think health care workers all have the same idea of what a near-miss is?

P: (Long sigh) Um, maybe they will take it as general term but will not use the word near-miss. Yeah. We all, oh, I thought this baby, we all though was going to die but look. I can remember some time ago, more than 19 years ago, a lady delivered preterm, a preterm baby. It was abortive as we were thinking. Very tiny baby. Those those times we haven’t got this unit. It was preterm nursery, post-natal unit and all those things. And the baby had ceased breathing. As we all know, preterm babies have a lot of apneic attacks. Those days the nurses working there I had them finish not quite long. So I didn’t even know the baby is dead or if this baby is alive. So we all think this preterm baby’s dead. So the sister who was in charge at that time had dropped this baby to us, where we were keeping the preterm babies. Then, the cleaner was going to pick something from that room. Then, she saw something moving in the cloth. Then, she called her sister, “Sister, come and look! There’s a baby here. I mean, something is moving in this.” Then, the sister unwrapped the baby and saw her. The preterm baby we thought was dead was moving, here and there. So I think (stammers) at that time, if ehh we had apneic ehh the gadgets we use to check apnea. I’ve forgotten the name. If we had had those gadgets, maybe we would have put the baby on it. And I mean, you know that the baby wasn’t dead. But this baby, the lady unwrap the baby, put the baby back. And the baby survived. It was discharged for the mother. So the situations where because we don’t know or because we don’t have ehh I mean, gadgets or strong eyes to see things, we do think, “oh, it’s dead.” Meanwhile, the baby survives. Some babies can have long apnea which you think is dead. But then suddenly, the baby can stabilize. That, this, I have ehh seen this, two [inaudible-31:29] occasions. The baby we all thought was dead, but we came around, it survived. Was discharged home.

I: Ok. Do you think the distinction of near-miss is a useful distinction for healthcare workers?

P: (Sigh) Yes. Yes. Yeah. But as I saying, if you are not experienced, if you are not experienced, you you you may miss those babies. Yes. Because you’ll be, maybe a baby will have this apnea. You’re bag and bag and bag and bag, this baby won’t breath. Meanwhile, the heart is still beating. We have situations like that. The baby will not breathe but the heart is not gone completely. And you say, “oh, this baby is not breathing so we’re going to leave the baby.” But if you are experienced or you have a lot of ehh skills, you can know that oh let’s continue this. We, well, I know I know if you bag a baby for more than 20 minutes and the baby is not breathing, it means that the brain is dead, yeah, the brain is dead. So no matter what you do, most of the time, these babies don’t survive. Don’t survive. So if nurses working in the NICU are experienced or have knowledge of neonatal care, I’m sure all these near-miss ones would be, we would we would get them surviving.

I: So if you knew a baby was classified as having a near-miss, do you think it would change how you manage that baby after their near-miss?

P: Yes. As I already said, these near-miss babies when we are discharging them, we tell their mothers that whatever you see in this baby and you are not satisfied or comfortable with it, bring the baby back. So most mothers do that. They bring them back. And we help them whatever problems they found at home. They they bring them and we help them.

I: Ok. Um what challenges do you think babies who experienced a near-miss will face as they age?

P: What?

I: What challenges do you think

P: Challenges. Um well depending on the condition that the baby’s brought in. Like severe asphyxia, paper white asphyxia, is able to survive. They have a lot of problems like difficulty in sitting, difficulty crawling, difficulty even holding their neck, difficulty in walking. There are milestone delays. They have a lot of ehh developmental delays. So most of them find it difficult to hear, some difficult to speak, so that is why we do refer these babies to the neurosurgeons. Ehh, I’m sorry, neurologists for them to help develop their brain better. We all know that the brain controls everything. So if your developmental age is delayed, you definitely need a specialist to help. So these are some of the challenges these near-miss babies have. Yeah, especially, I’m just giving asphyxia as an example. But like preterm babies, wow, already everything in them is premature. So they are they are behind, the normal babies. So their milestones will be a little different from the normal-term babies. Those are some of the challenges.

I: Ok. And do you feel like the uh, the healthcare system will be able to respond to these babies’ needs if they have problems as they grow up?

P: Um. Hm. Our system, it would be a little difficult for some of them. Depending on the challenges that they are having. But you don’t have a lot of specialties. I mean, special care areas for these babies. Though we have some in our hospital set up here. There are a lot of, some of the problems that we can’t handle, yeah. And something like, I know a friend’s child who had asphyxia. And this child is autistic. Unfortunately we don’t have any autistic school in this community. If the parents are not wealthy enough to take this child maybe outside. I mean the child is going to face a lot of problems, because with his age, he‘ll be playing with the age-mates, but it’s difficult because the child can’t talk. The child can’t talk. Meanwhile he’s attending school, the normal children. So he’ll be ridiculed. I mean, “Oh you, you can’t talk, you can’t.” You see children, how they behave yeah. This child, we all know autistics, how they are. Their attention span just ehh a little. They have this short attention span. They are always on the move. They’re always on the move. So these parents are finding it even difficult to have another child. I don’t know whether that is telling on them or they are not getting the pregnancy themselves, I don’t know. But it’s a very huge problem for these parents. They are very close friends of mine. I know another autistic child whose parents are wealthy. They have a lot of money. That child was their last born. Because they have money, this child is in a special school where they take care of autistics. And some time ago, I contacted them. They said, “Oh, now he can do this, he can do this,” which initially he couldn’t do. So it will depend on the family and the community as well. You know, this autistics school that I’m about, it is in Accra. If these parents are in Kumasi and they don’t have the means. They can’t send their child there. So it becomes a problem for them, yes.

I: Ok. Um. Do you have any other overall comments on, you know, babies that look like they would die that live instead that you would think uh is important for us to understand for the study?

P: Yes. Yes. There are, if, for understanding this study. Yeah, it is very very important. I I I believe the outcome of this study can really direct us as to how to take care or handle these bab—these near-miss babies. Yeah. So this study is very very important.

I: Yeah. So do you think there’s anything else we need to know?

P: Um, concerning the near-miss? Oh, well,

I: Just like anything you might have not been able to say?

P: Well, to me, if the there is any fund, there’s any fund for the unit that can really help. Or even if it is not a fund, per say. If there is a special ehh, how do I say. It all boils down to the fund. Because like I was saying, some of these babies may need some drugs which the parents can’t afford. Yeah. ‘Cause they tend to need strong antibiotics to kill some infections here and there. Because most of them have infections. So if the parents don’t have money to buy these expensive drugs, then we we can’t do anything for them. But if the ward or the unit has a fund or some help, some form of help, for these babies concerning drugs or any other thing. I think it will help survive, I mean the survival rate of these near-miss babies.

I: Ok. Well thank you for your time and for answering our questions. We really hope these answers will help us understand more about why some babies live instead of dying. Uh, please let me know if you have any questions. And if you have questions in the future, I can be reached through Dr. \_\_\_\_\_\_ or you can ask her questions as well. Um, so that’s it! Thanks again.

END OF INTERVIEW

Type: HCP Interview-KB9005

Date: 26-06-2015

Position: Nurse

I: Thank you for taking the time out of your schedule to meet with me today.

P: Welcome.

I: As uh Dr. \_\_\_\_\_\_ probably told you, this project is focused on learning more about babies who have life threatening complications during and after delivery, but who survive. Your thoughts and opinions about why some babies survive while others die are very important to helping us understand these issues better. Uhh, like I said I will be recording the interview. This is just so that I have something to help me remember what we talked about and I won’t have to take as many notes. Uhh just so you know, the recordings will never be played publicly. We will transcribe them and then destroy the tapes. If there is anything that you don’t wanna talk about, please let me know. Also, we can stop the interview at any time. Please let me know if you would like to stop.

P: Alright.

I: What we talk about will remain confidential. I won’t share the details with patients or others at the hospital. You will not be named in anything that is written about this, the research. Um and just so the tape knows this is KB9005. Uh ok, uh so we would like to learn more about your experiences with babies who are ill and their outcomes. You’ve been working on the NICU for a while now. Uh some of the babies have had severe complications. Some of them, you may have struggled with and they died. Some of them, you may have struggled with and they lived. Some died no matter what you did. Some lived when you thought that they were going to die. What do you think was difference between those who lived and those who died?

P: Wow, uh I will say depending on the the… eh the condition of the babies or who come and then the availability of the parents when we need drugs for them, mhmm. If they are around, some of them eh like let’s talk about maybe a preterm baby you know it’s good for them to start feeding early, mother is not available, we need money for treatment. At least if mother is there for them to start the EBM. For them it’s it’s something good. Medications that we need for the baby, maybe complication, mommy has they have to buy meronim and stuff like that (clear throat) then there the parents are not available to buy those things, then those are some of the things. At least if the parents are there, and they are able to provide the things we need for the child. It’s goes to a far end of providing making a better choice for that baby whether to live or to live mhmm yeah. (coughs)

I: You said um to buy EBM, what is EBM?

P: Eh Express Breast Milk

I: Oh, so like formula?

P: Yeah, no not formula, the breast milk.

I: Oh.

P: Uh huh, the little ones you know we need the milk the milk is better than the formula, uh huh but there are sometimes that the parents are not available then we have to start with the formula, which is not good for them you know. So those are the points. So if the mother is available, for us to start feeding early that baby it goes to improve the babies condition, [cutout-3:38] medication, they are there to buy it, some of them are expensive. When the parents don’t have the money to buy them those medications for their child then uh we can well well if we also have something stock uh huh then we can also do our best but our best never goes that far, you know.

I: Mhmm.

P: Yeah, that’s what (mumbles the rest).

I: Ok, can you tell me about your experiences with those babies who lived when you thought they were going to die? Which diseases or conditions did these babies have?

P: Oh we have, we talk about preterm, birth asphyxias. There was, I remember one preterm that we all gave up on. There are days that we we thought the baby was gone, they will sign the eh what they certify the baby as dead you go in when you are ready to put the baby out he will come alive again. I mean oh for uh have that experience about twice, but he was able to make it. I think the other day he came here, he was about ten years old or something. He came here to celebrate his birthday with us. It’s a boy. So there are occasions that you thought the baby is going but they are able to make it mhmm.

I: That baby that came he’s like ten years old now, did he have any other problems after that?

P: Ummm uhh, I think he’s a little slow mentally mhm but everything is fine, yes.

I: Ok, um is any other special care given after their diseases or conditions are resolved?

P: Uhh normally when we discharge them, it depends on eh the condition of the baby when he was discharged. But some eh the (coughs) birth asphyxias, sorry, eh you have them you follow up you follow them up at the neuro clinic for some time to see their eh what do you call it, neurodevelopmental stages and stuff like that. Um the preterms too, uh they follow up at the NICU clinic for some time to see how they are developing before finally they discharge them (coughs). I’m having some issues (referring to cough).

I: It’s ok oh. Sorry. Um, are mothers given special instructions for caring babies that lived but you thought [cutout-6:32]

P: Special instructions, um mmm, uh not exactly. Not exactly but, well depending on what is wrong with the baby. Whatever is going on he will need some special instructions, we do that. But I don’t think there is any special thing. We only maybe ehm like the birth asphyxias you have to tell the mother the sort of condition and what to expect. Maybe he may not be like the normal children that the mother has seen. Maybe if he has had he has some children already and the developmental stages of that person will be slow it wouldn’t be like the other ones uh huh. So maybe those are some of the things you have to inform, the babe he’s not seeing, he’s not playing like how maybe he’s talking, he’s not talking, walking everything is slow, then this is what the parents shouldn’t expect so much, you understand? You inform her these are the sort of things that maybe you maybe seeing, probably. Probably you may be seeing so that it doesn’t come as a surprise to the person that this and this is what is going on, yeah.

I: Mhmm, so when you discharge the um babies is there anything you make sure besides you know what to expect is there anything that they need to make sure their doing to help babies survive since they almost died?

P: Um…hmm…eh no I eh I, it’s just the normal things that we tell them to do. Caring of the child, maybe infection, protecting the child from infection, she herself, the mother, how to take care of herself then take care of the baby. Those are the normal things that we tell them, unless maybe there’s something particularly wrong with the child, then you have to inform the mother how to take of their child while she goes home.

I: So in cases where there’s something particularly wrong and you have to give like those kinds of instructions, do you find the mothers are able to follow those instructions?

P: Um, well um they are here with us so at least we try to teach [cutout] so that they go home. So we make sure that maybe that person is conversant, will be able to do what we want her to do when she goes home before we discharge, mhm, yeah.

I: Ok, so for the for the moms that don’t follow the instructions, what is usually the reason why?

P: Um…the reason why. Eh some of them, maybe they are not particularly eh interested in their child. Mm so well whatever you do, it’s not interested. So when you you sometimes you have cases like that. In the long run, some of them, they will just abandon the child, they will run away, they will leave the child with the hospital. I remember a case where we had, I think the child was blind and congenital yeah from birth, and then um he had um uh there was another condition in the child and they didn’t want the child. So it’s like she just went home and never came back again. At a point she came, we have to follow up, we followed up, and she came around but when she came she was just trying to make herself available for some few minutes then she want to run away again, so we have to force her to take the child. By then the child was fine enough to be discharged uh huh but because of the defects of the child, they didn’t want it, mhmm. So there are times that you have cases like that. Like today we have there was a baby with, she hasn’t got any limbs, mhmm. You know what he said, the grandma said they should kill the child.

I: Oh!

P: Yes. So you always have cases like that. So today when they came one of the nurses was able to tell her they should come and take the child home. They force her to send the child home, so with a child like that, what do you think is going to happen? Maybe when they go home, you can imagine mhmm. They don’t want the child in the first place mhmm, so we don’t know what is going to happen, but we have given them out. So most of the time cases, cases when you have abnormal children, babies with problems, when they come and see their child they will stay awhile and we won’t see them again, they leave the babies, and then, that’s the end. So we take care of them for some time then we…let the social welfare people come in then after that they are taken to the children’s home, yeah.

I: I’m not sure if you would know or not but at the children’s home are there like is there someone there to look after their care, any special care they might need now that they have been discharged?

P: Well I, eh how do I say we haven’t followed up but I think since eh that’s their job, too. I think they have people like that, yeah for them, who really take care of those special kinds of cases, yeah.

I: Mhmm, ok so besides like um when sometimes the babies aren’t how the mother expected, do you think there’s any like cultural barriers that prevent mothers from following instructions that they need to follow?

P: Um well you know in in our situations, in Africa, when you have those kinds of um children it’s like it’s from your home. Especially the woman, so I mean it’s like eh how do I say it? You don’t come from a good home or um there’s something in your home. So if we even with that issue, they can divorce you, yes. Because when your offsprings are not good. I mean if eh they started having children you are bringing that kind of eh people into the world then what is the essence? ‘You are not going to give me anything better’, you see. So it’s like when it happens that way, mhm so this are some of the cultural eh problems. When you go home, I mean in you know in Africa when we have children people come around and they are coming to see and stuff like that to celebrate with you. Then when they come, you have this kind of abnormality, it’s some kind of eh it’s a disgrace eh or something like that, so nobody wants that. Nobody wants that. So I remember we had eh eh um what was it… Oh what was the name? Um those with the short limbs (tries sounding it out), oh the name is not coming. Um the daddy was here, he came to see the baby. You know what he said? He said he cant take this kind of person home, if we have somewhere to send the child, we can do it. He wasn’t ready to accept that person in his family. So if you are the woman, you eh definitely should know you you have a problem, yes. That man can decide to leave you because of that child, yes. So it’s this are some of the cultural problems. Like you don’t have something good from your home uh huh, that is it.

I: Ok, um have you ever discussed uh one of these cases of babies that survived when you thought they would’ve died with your supervisor or a coworker?

P: Uh, discuss?

I: Yeah, like ‘Oh that baby, I didn’t think they were going to make it, they made it!’ And so you talk about the case.

P: Oh well…eh it happens sometimes, eh there are times we are all eh anxious so we we become happy if someone eh like this particular baby we are talking about, that went home. We all thought he would die, even the mother. We had all given up on the child. But he was able to survive so sometimes on his birthdays they come they come around yes for us to see how he is doing. So it’s a joy to us that at least we have someone like through our efforts and the mother’s was able to go home, you know. So there are times we talk about such things, mhmm. I remember we had ehm this mother too who also had the same child with no limbs, yeah. So I lent, I had a video, a video where a lady I don’t, what was the name? I can’t remember the name, but she she was an African American or something like that. The sister was uh eh she was um uh I think it was eh, what did she do? She was a swimmer or the mind is not stable, I can’t remember what she did. But eh…she was able to make it, not knowing she was even the sister, that particular lady. She was abandoned because they hadn’t any limbs, the parents abandoned her in the hospital and this white couple decided to pick her up and they took her away yeah. So eh so yeah so she did acrobatics, you know. Yes, I think I may have the video here, yeah so she did that and she was famous. Not knowing that particular lady that she was her mentor was even her sister, yeah. So I showed that picture to her because she doesn’t have limbs doesn’t mean she’s useless. She can do something, mhmm. This is what somebody has been able to do. So she too she can do something, you know. So we encouraged her and she was happy. She took her child home, yeah. So ehm unfortunately I haven’t seen her since she left, I didn’t follow up so I don’t know how they are doing now. But she was happy taking the child home, but if it were to be somebody because of this problem, she will just run away. Normally that is what they do. They are happy the child comes here you know. So either they will come here or they won’t come at all.

I: Mhmm, when you and your members of your team discuss cases like this, what is usually the outcome of the discussion?

P: The outcome…Oh uhh I think the outcome uh, what can I say. We are happy we are also encouraged that at least our efforts are not in vain. We talk about it to encourage ourselves, yeah, yes.

I: Do you, do you all talk about um, new way, like ok this baby lived um what did we do maybe that is the reason why they lived, do you ever discuss things like that?

P: Uh, not exactly. I don’t think so, yeah.

I: Ok, have you every received formal training on how to handle these cases of babies that survived when you thought they would’ve died?

P: Mm no…

I: No, ok. Uh, do you think there should be more training on how to handle these cases?

P: Well I think so, yeah.

I: Um, what kind of training do you think would be useful?

P: Um…eh well I think uh…I don’t know maybe [cutout-21:35] outside maybe you have uh I don’t whether you have eh how do you call it? Maybe special unit for those kind of cases and the how they are nursed. Maybe you may have something like that so it will to be good for us also to experience those kinds of things. It will be of great help, so so that we know what we are dealing with, the complications, yeah. Then uh I think it will help us more, mm when we are nursing them, what to do, what to expect, then how to eh the mothers, when they come in, what to tell them. Though we have some experience but I I don’t think ehm knowledge knowledge is always power so its good if you have more knowledge on something. It gives you the power to do more. I think it will be good if we have some training on this kind especially these birth asphyxias, their complications, what to do, what to do, and what we need to do. Things of that nature, mhmm.

I: What do you believe is the most important thing to understand in order to handle these kinds of cases?

P: Mm, the most important thing to understand to handle these cases?

I: Yeah, babies who lived when they looked like they would die.

P: …Um…um how do I understand that (laughs). Um the most important thing for you to know…eh like I’m saying knowledge is always power. So if there is something new, we’ve been doing it the way we know [cutout-23:57] but we have to know. It will help us better, yeah.

I: Ok, what do you think is the most important thing for mothers to understand when you’re discharging these babies?

P: Uh like I said uh if we’re talking about the eh the birth asphyxia the neurological development, yeah. So if you know you, know how this children progress in life, yeah. You will be able to tell them. Expect this, if you are seeing this, you are not seeing that, don’t be discouraged, it will take time and stuff like that, you know, yeah, mhmm.

I: Are you familiar with the term near miss?

P: Near miss. Um not exactly, I think I’ve heard it before but I cannot remember what it is.

I: Well it, what do you think it is? I mean it’s ok if you get it wrong.

P: Umm…help me out (laughs).

I: Ok (laughs), so a near miss is when a baby you just you did not think it would make it but it it lives anyways so it’s like you nearly missed them.

P: Ok, ok, ok.

I: Yeah, so do you think healthcare workers all have the same idea of what a near miss is?

P: No, no…I don’t think so.

I: Ok, do you think ok so some some healthcare workers may not know the word near miss but do you think they separate, they make a distinction, between babies that are ill and babies that are very ill that you though would die but they lived. Do you think they make a distinction between those kinds of babies?

P: (sighs) No, I, I don’t think we can make that eh distinction because there are times you think um you think a baby is stable enough to leave but then suddenly it will die. Then there is somebody who is very ill you think this person, tomorrow by the time you come in, they will not be there. But he will be there and he will home. So you can’t exactly say that you can distinguish between them, yeah.

I: Ok, um so do you, if that distinction did, if people use that distinction do you think that’s helpful as a healthcare worker to make that distinction?

P: No, I don’t think so, I don’t think its helpful, yeah.

I: Why not?

P: Well if um if you are thinking somebody is very stable so perhaps you are giving your attention to the person you think is so ill and then only for you to realize that the other person who’s your attention you thought he was so stable rather turns bad and then just dies [cutout-27:35]. I think you won’t be happy, yeah so, I don’t think its eh it’s good for you to start distinguishing that this particular baby is ok, so let me turn all my attention to this one, yeah.

I: So if you knew a baby was classified as having a near miss do you think it would change how you managed that baby?

P: Um…um well, since we don’t want to have the near miss (laughs). Eh well if we know if we particularly know that this is the situation, I I think you devote more time, yeah, mhmm

I: What challenges do you think babies who experience a near miss will face as they age?

P: Yeah uh, I think…some of this neurological development. Maybe their speech, it will take time for the person to talk. The, maybe some of them, maybe walking, schooling, it all effects them, yeah.

I: Um how do you think the healthcare system will respond to their needs?

P: Healthcare system, mm…I don’t get the question well, how…?

I: Like when you said they need like all those extra things…

P: Yes.

I: Do you think the healthcare system is prepared to provide those extra things?

P: (sighs) Not exactly, I don’t think so…I don’t think so. That is all I can say (laughs).

I: (laughs) Why do you think, why do you think not?

P: Um, well I don’t think we have the eh eh we have the facilities here for such those people yeah. Something we have to [cutout-30:29] it will help them. That is all, that’s what I can say.

I: Ok, uh so do you have any other comments about babies that have had a near miss that you think would be useful for us to know for the study that were doing? Just anything overall.

P: Mm, anything useful…I’m now gathering my thoughts (laughs) uh…um I think eh if you are able to um bring out some of the complications that they go through in their later part of life, eh then they can bring that into their policies for them to make eh factor those things into their policies for them to [cutout-31:43], yes.

I: Ok, again thank you for your time and for answering our questions, we hope your answers help us understand more about why babies that seem as though they would’ve died, live instead

P: Ok.

I: Do you have any questions?

P: Mmm, no.

I: Ok, well if you have any questions in the future you can reach out to Dr. \_\_\_\_\_ he will have my contact information if you want to as me anything as well.

P: Ok, yeah, thank you.

I: Thank you.

P: I hope [cutout-32:14]

END OF INTERVIEW

Type: HCP Interview-KA9006

Date: 30-09-2015

Position: Doctor- Junior Specialist

I: Great, thank you for taking the time out of your busy schedule to meet with me today. Uh so, as I’m sure you’ve been told, the project is focused on learning more about babies who have life threatening complications during and after delivery, but who survive. Your thoughts and opinions about why some babies survive while others die is very important to helping us understand these issues better. Uhh, as a reminder, I will be recording the interview. This is just so that I have something to help me remember what we talked about. I also will have to take as many notes, more so just notes so I know what to follow up on. Just so you know, the recordings will never be played publicly. We will transcribe them and then destroy the tapes. If there is anything that you don’t want to talk about, please let me know. Also, we can stop the interview at any time. Please let me know if you would like to stop. What we talk about will remain confidential. I won’t share the details with patients or others at the hospital. You will not be named in anything that is written about the research. And just so the recording knows this is interview KA9006. Um, we would like to learn more about your experiences with babies who are ill and their outcomes. You’ve been working on the NICU for \_\_\_\_ continuously now. Some of the babies had severe complications. Some of them, you may have struggled with and they died. Some of them, you may have struggled with and they lived. Some died no matter what you did. Some lived when you thought that they were going to die. What do you think was the difference between those who lived and those who died?

P: Erm actually it all depends on the problems that they come with and sometimes too delay in seeking medical care. You see some of them they come in very ill, but then erm they are not referred here early. Some of them are even referred early but the mothers don’t bring them early. So erm assuming they are asphyxiated, the parents take them home a day or 2 and then you realize they are not feeding at all and then they bring the baby back. By that time, this baby would have starved for some days and haven’t received anything. So they come in very ill, very bad. For some such babies, we usually have to resuscitate for a longer period before they are even able to get a spontaneous breathing and capsulate and all that. So for these babies, most of the time, we loss some of them, although some of them survive and usually it’s quite difficult to just say what the difference is. Is quite difficult to say what the difference is. And then for some of these, I think that what mainly makes the difference is how fast they get here. A lot of them the support they get if it’s a referral from the hospital, the support they get from the hospital. Example is let’s say you are transferred from other facility and you are referred here. Then the child is sick just for let’s say oxygen, and the child comes with no oxygen. The child is very green, actually has stopped breathing for some days before brought into the hospital for us to start the resuscitation. It becomes more difficult but if this same baby comes early and maybe on oxygen. Maybe there is ambu bag and there is a health professional accompanying and is even bagging and they get to this place, the outcomes should be better for those who came in with that and they are just rushed here. Just a longer time to resuscitate and goes to them, so that’s what I see.

I: Okay, can you tell me your experiences with those babies who lived when you thought they were going to die, which diseases or conditions do these babies have?

P: The most common among them I will say is asphyxia the severe asphyxia, some of them, can be very bad so a day or 2, even spontaneous breathing becomes a problem. Then for these babies, sometimes through intermittent bagging for them, some of them do survive. But most of them, most of the time we are not expecting that because of their very bad condition. But some of them, the little bit of support you give; it takes a longer time for them to recover. Some weeks, some up to even a month, but then some of them are able to go through. So most of them are severely asphyxiated and also, babies with Jaundice, with the evalopathy, some of them come in very bad. But then after the exchange transfusion, others: some of them are able to push through. Just that for them, we have to really the volume of blood we are exchanging per cycle. Sometimes we have to reduce blood to about 5mls per cycle. Although the exchange will take a longer time and the supportive treatment will also take a lot of efforts. Some of them are able to push through. So for this group of babies, especially those who come here with severe asphyxia and Jaundice, some of them are able to go through although we thought they will die.

I: Ok, is any special care given after the disease or condition is resolved?

P: Yes, for these babies, usually follow them up for longer period. In our neonatal clinic, usually the baby is up to about 3 months and then we discharge them. But for these babies, because we want to access their development, we usually continue the follow-up to about a year or 2. It all depends on how… Some of them, they have to put on erm anti-seizure therapy for some time. Because some of them may go home early and seizure disorders and all that and others too may have to get the physiotherapy because they may have disabilities. They have developmental delays so for them, we have to do a lot of physiotherapy and follow them up. So that that they gain their developmental milestones. Although theirs are delayed, some of them, as they grow, sometime they are able to pick up although it will take some time. So we follow them up, some of them actually 2 weeks before we even discharge. But for the normal babies, no time to: like 3 months at best, we had discharged them.

I: Are mothers typically given special instructions for caring for babies that live but they should thought they were going to die?

P: Yes the mothers are counselled before they leave here. But because of the condition of their babies, we will have to follow them up so we tell them right from the word go that this baby you have to be coming to us more often. We will discharge the baby home alright and there are setting things that too that they have to look out for. Because some of the babies survive alright but even sucking of the breast becomes a problem. So this mother may have to continually express the breast milk, give it by a can and all that. And so for them, we counsel the mothers about some of the things that they may have to look out for when they go home. Or some of the conditions that even from the hospital, they know that their babies are not crying like all the other babies are doing. So for them, we counsel them, and then there are things that they have to also look out for. Like the developmental ones too because they know in our society, let’s say we are in the same house and having children around age and the baby has started: the other baby has started having head control, the mother is able to bathe out of bath and all that. But the other baby, because of the condition, will not have attained those milestones so we counsel them. For them to know that for this reason, your child will delay its development so just calm your nerves and come to us as often as possible so that we can continually counsel them. Because when you counsel them ones, I bet you by the next day, they will tell you that you didn’t say anything. They would have forgotten, so we continually counsel them, when we meet them at the consulting rooms and it’s a continuous process. And then we try to intervene as early as possible. So if we realize that there is no: the tone is very very low, then we have to start a physio then. Others too gradually, the child will pick up himself so we just give the mother time. But if we think that this child needs additional care we go on early, pick them up early and then we transfer them early, so that these babies can be rehabilitated early.

I: Do you feel like the mothers understand these instructions?

P: Sometimes yes, sometimes no, it all depends on the mother. Some of them are: can be very anxious so whatever we tell them here, when we ask them again, they will tell you that, they were never told them, they never understood anything that you said, that’s how it is. But working here for some time, we’ve come to realize that what we can do is reinforcement. We’ll keep talking to them, because when they are admitted here at first, they are very anxious. Let’s say the baby comes very asphyxiated and all that, they try as much as possible to establish breastfeeding. Sometimes you are able to, other times you are not able to. So the mother will have to do the cup feeding and all that. After everything is said and done, the mother realizes that she has spent a lot of time on the ward. Let’s say 2 weeks, let’s say one month, the mother is anxious to go home. So we will counsel her and tell her to go and come back in a week. In a weeks’ time, you see her in the consulting room. And all that you told her about the fact that oh this, then she will come and ask you again actually. Oh my baby is unable to suck well, my baby is unable to cry, when he is hungry he doesn’t cry, meanwhile you told her everything before she left for the house. She will tell you that oh: then she will come and ask you. Then we will take the opportunity to actually do the counselling again to reinforce her to do them. Because if we leave her like that we said that oh I told you the other time, she didn’t get anything that you said because she was very anxious. You understand, staying here, I mean knowing that your child is not well and all that, it’s gives them a lot of psychological… So we also understand them to some extent so when they come, we try to reinforce what we have told them to counsel them again.

I: Ok so besides what you already covered, if mothers don’t follow the instructions, what is usually the reason why?

P: Thus is multi factorial, sometimes, even the educational level of the parents too factor here. Some of them, no matter what you do, no matter what you try to do, it’s very difficult for them to do it. It’s very difficult for them, apart from so many things; their educational level is part of it. And sometimes too I think to some extent, some of them suffer from postpartum depression that we are not able to pick up. So for these mothers, she’s already very depressed and you go and go on and on and on about the child and the things she has to look out for. The mother is not psychologically sound to pick all these things now. So sometimes what we do is that if we have: if there is some support around, let’s say the mother or something, then we try to counsel them together so we counsel the other person too. But sometimes we don’t find anybody like that. If in that instance, we counsel them although and we discharge them, and when they come back, usually they don’t come alone. If they come with somebody, then we take the opportunity to counsel the person too in addition to her. So we realized that some of them, the anxiety, the psychological issues surrounding their birth also: especially some of them don’t really have support because they think that the child is very sick. The husband is nowhere to be found, and if the husband is even around, the husband will tell you that I don’t have money, you are staying so long. So the mothers turn to be accompanied with pressure because of the lack of support that they are having from their families. So because of all these factors, some of them, your counselling may not go down very well with them.

I: You said like some of them suffer from postpartum depression that’s hard to figure like what are there, why is it difficult to notice they have postpartum depression?

P: that’s difficult to, ok it’s not so obvious, because sometimes, when they come, I mean we all know when the mother’s child is not well, no mother will be happily going about. Every mother to some extent will be worried about the child’s condition. So it’s not so easy to just say that once your worrying is not normal than this, because all of them worry to some extent. But then when you are with the mother, and you be with them for some period of time and then you realize that this mother let’s say we have discussed with her. Because with the management, the mothers are there with you, they will tell you their problems with the baby, maybe this baby is not crying, this baby is not sucking, everything. Then you try to counsel her even on the ward, tell her oh what is this is what is happening so this is what we are expecting that the baby will take some time before it’s able to do all this things that you are expecting the baby to do. Then the next day, coming the mother is very worried, very down. Some of them will actually weep, some of them will be actually crying. When you ask them, and she tells you the same thing that oh the baby in not well. Meanwhile you’ve talked about it the day before. Then you realize maybe this mother’s worrying and all that is not just because of the baby. So it’s not that it so difficult to pick up, yes it can be something, it can be very very something because some of these mothers may not really show their emotions when you are with them. We talk to them; they will be as if they’ve understood everything talk we’ve told them. And so you are happy, but then you come the next day and you realize that all that you talked about didn’t really go down with them. So for some of them, we are able to really say that, as for this one, but another challenge we have is that even when we pick them up, we don’t even the psychologist at hand to really talk to them. So we turn to become the psychologist ourselves. Because we need them but that it’s to a lesser extent. We are not able to really, if we had the clinical psychologist stationed here, the person could have even taken over. Because we really need to do a lot of the counselling, we do it to some extent but we know that more could have been done for such people.

I: do you feel like there are any cultural barriers to make the mums understand your instructions?

P: Erm… yes there are, there are because sometimes the mothers have got a really conceived idea that this is what is happening to the baby, is from the traditional or religious whatever. They have this disease they call “asram” no matter what you say, this baby has got “asram” that’s the mother’s point of view. Her stand point is very difficult to actually brand that idea and tell her that, oh maybe it was because of a difficult problem that you had and so for this baby, we have to follow up for a long time. Because she thinks that it is this particular condition, some of them will not even come back for the follow-ups. Some of them we lose them to follow-ups because they think that it is ‘asram’ and so they have to go in for traditional medicine to be able to help the baby. Some of them, because of some of these traditional things, they don’t even have bring the baby to us early. They would have done all sorts of things before the baby gets to us. By the time the baby gets to us, the condition would have been very bad. Some of them, we lose them; others were able to save but not all of them. So it means that cultural practices are barrier to some of these things, it makes it very difficult to us.

I: When did you said it’s called?

P: asram

I: can you spell it?

P: asram

I: Have you ever discussed one of these cases of babies that survive when you thought they would have died with your supervisor or coworker?

P: Yes, usually it’s done; they’re usually our problem cases so we discuss them.

I: Ok and if you and members of your team discuss these cases, what is usually the outcome of the discussion?

P: Erm usually when cases come out to be that, our primary aim is the morbidity that can be associated with it. Yet we’ve been able to save the life. But then the future outcome the future outcome is something that we usually pay particular attention to. Because of these things that we have discussed, because we really: we really have to follow them up. Because if we just say that oh we’ve saved them so mother take baby, go home, we all know that it usually doesn’t end up there. Because in the future child can come to the (inaudible) for whatever condition it’s suffering from. So that’s what really we usually look out for. Because you know after the practice here, at least the little that we can do, we did for the baby and the baby survived. But then what happens in the future. So it’s the follow-up which is very important to us. But we are limited in several ways because as I said, some of them are lost to be followed up. Although we try to get the particulars and everything after some time, we even try the phone number and it doesn’t go through. And all those things are challenges to us, so for these babies, the long term outcome and how we can follow them up. So we get to a point where we are satisfied, the mother too, the parents too are satisfied that the child is well, that is our main challenge.

I: So has there been any way to get around that challenge, I mean it seems like something is pretty different, like the barrier of follow up?

P: it’s quite difficult you see in our country too, the address system and all that becomes a little bit challenging. So the best is let’s say a small number but some of them will not give you any phone number. Some of them, and some of them will give wrong phone numbers, some of them maybe it’s right, but when you try it, it never goes through. So the follow-up has always been very challenging. But what we do is that, we try to encourage them as much as possible, to come for these follow-ups, because it’s only when they that you can get them. When discharged, and the mother doesn’t come back again, it’s quite difficult to know what really happened to the child. So we try as much as possible to get them. And apart from just their numbers, we try to get their partners, or their parents, try to get their contacts so that we can through them to contact the parents.

I: Have you ever received formal training on how to handle these cases of babies that survive when you thought they were going to die?

P: No, no formal training is it’s just like on the job training. I mean when you meet a case like that, then you try as much as possible to follow-up as long as you can to find out the outcome of the child. So it’s just like on the job, no real formal training.

I: Do you think there should be formal training on how to handle these cases?

P: Yes I think it will be good, I think it will be good yes we are trying our best but I believe if we have a formal training, then we can do a lot more. Because I really believe that there’s a lot of room for improvement. Because there are several issues that surround these babies, if you really have formal training, then we can tackle it from all points of view. Their cultural, the social, the psychological, everything, we can really tackle it more perfectly. So I think formal training will be good.

I: And so what kind of training do you think there should be?

P: that kind I cant…

I: like what do you think should be thought during the training?

P: oh yes, I think that during the training, we have to especially talk about how psychologically, we can handle these problems. The psychological training will be very good because every mother would have gone through some psychological: the effect of the child’s sickness will have some of the psychological state. So it’s better: it’s best that we go through psychological training. Also it best that we can know all the cultural practices around us. We are educated on it so that we are equipped so that if the mother comes from this point of view, then you also, because you are equipped already, then you’ll be able to tackle it. Be on the same level with her and be able to bring her up to the knowledge that you also have. So it’s very important, I think I think the pointed psychological training should be there and then other other things. Even in our follow-up, what really should we in the partridge although yes we say that we are following the child up and logically. What really should be in partridge, because we ask, when they come, we ask the mother one or 2 questions and then sometimes we just let her go because of so many things. But if we really know that that’s the stipulated thing that we look out from these babies, I think it will go a long way to help.

I: What do you believe is the most important thing: the most important things to understand in order to handle these cases of babies that survived when you thought they are going to die?

P: the very important is...

I: Just to understand a lot more

P: Where do I start from, from the referral sites or from the parent themselves or from the obstetric point of view?

I: all through it

P: all through

I: yea

P: then right from the obstetric point of view, I think that our colleagues who also take care of the mothers should also be a little bit more interested in the babies. So when you deliver, the mother is fine and all that, then you have to also check whether the baby too is in that same state. If the baby is not, and you think that he needs help, I think that you can go straightaway, maybe refer the baby early enough so that we can also do our parts in saving the life. Because we believe that when all: if the delays in referral, delays, all those things are cured it will really help go a long way. (phone rings)

I: yes so you were saying from the

P: obstetric point of view, if the delays with even mothers who have maybe suture distress and all that is cured and it will also help us because the morbidity that will come out of the births will all reduce. And apart from that too, the: yes so the referral cases too will delay. You think that is not doing well, just refer the baby to us early or let the pediatricians treat early so that whatever soon is done to help the baby, is done early. And then apart from that, the parents too some of them delay themselves. Maybe go home there’s this baby who is not doing so well some of them may delay because of their cultural practices they want to do give preparations to apply things to the baby and all that, before the baby is brought to us. So by the time the baby reach this place, it would have generated to a very bad extent. Because they decided to take a long time, some of them if we had seen them earlier, I think the outcome of the whole management would have been better. So I think that from all this point of view, there should be a clearer understanding so that we can all help her before the baby is brought to us.

I: ok. Are you familiar with the term near MISS?

P: Yes but it seems it’s more adult domiciling than in the neonatal period.

I: mhm

P: I think I know near MISS, like when a baby comes to: the near MISS I know is immunizations, when babies let’s say they attend to it babies here and then they are been discharged. It’s a near MISS if you don’t immunize them before they go.

I: ok

P: yes

I: ok I mean well that could be from immunizations point of view <cross talk>

P: point of view

I: So like a near MISS, looking at a neonatal near MISS or maternal near MISS and so like a neonatal is when a baby you thought it was going to die, like you’re like it wasn’t gonna make it but it does. It survives so it like you nearly miss. Do you think healthcare workers all have the same idea what a near MISS is?

P: No I don’t think so, it all depends on how much effort given in trying to save a particular baby. Because assuming a baby, sometime, I mean to some extends yes. But I don’t think to all extent because if you see a baby and it’s very bad, and you resuscitate for let’s say it 2 hours, the baby survives. You will say it’s a near MISS, that’s what you determine it. But then assuming this baby came in quite earlier and then there were some delay, because here too we can’t say the system is perfect. There can be delays because sometimes they come in, they are supposed to get this medication, they don’t even get because there isn’t some at the pharmacy, the mother wasn’t available to buy the drug and there was no relative around. So the medication is delayed for some time and the baby deteriorates and then you come in, the medication then come in and then we are able to administer it and then resuscitate this baby and the baby survives. In actual facts, yes it’s also a near MISS to some extent but then all the things could have been curtailed here. The baby had been: if the medication had been served earlier so in actual facts, it’s a near MISS but to some extent, is not so I don’t think all of us will have the same point of view concerning the near MISS. It’s all depends on when you saw the baby, what you did to prevent the mortality, that’s what I think.

I: Ok do you think having the distinction of a near MISS would be useful as a healthcare worker?

P: Yes I think it will help us a lot in that it will help stopping a lot of delays and all that. Because we know let’s say if you have a clear cut near MISS, then you know that maybe this baby is not a near MISS and if efforts if out in or let’s say interventions are put in earlier, then this baby may survive. Then you don’t say that it’s a near MISS, then you’ll rather put in the interventions when the baby survived. But then there are setting cases that it’s no fault of let’s say ours. The baby came in a very bad state, a very very bad state so we needed to do all that we could. Resuscitate, give medication, everything in our part has been done and then the baby survives then we can say it’s a near MISS. So if we are going to get a very clear distinction, it will help all of us, because then you know that before new baby come, before I classify, it’s a near MISS, I will have to do ABCD, and then you do everything. And then you know that you’ve done all this and the baby survived. But then if things are delayed and then the child deteriorates and then interventions are then brought in although they are still brought in and the child survives, then you shouldn’t really say that it’s a near MISS. Do you understand?

I: ok if you knew a baby was classified as having a near MISS event, do you think it would change how you’ll mange that baby?

P: Please the question again, if you have…

I: Yes if you knew a baby was classified as having a near MISS, do you think it would change how you’ll mange that baby after?

P: Oh yes, afterwards yes, because for a near MISS baby, you have to (inaudible) more than for a baby who let’s say came in, you just put in your interventions and the child’s progression was just as you expected. You expected that the child gets better than you know and the child gets better. Then that one you are not so… but if it’s a near MISS, then you know that you can there can be consequences so we have to look out for them. Yes so for them, the management will now be stated.

I: Ok what challenges do you think that babies who experienced a near MISS will face as they age?

P: Most of their challenges are ideology, in our setting most of the challenges that we face are ideological. We realized that when they come in, when they are young, usually what affects them, what affect their brain is what becomes a problem for us. Because apart from that if the baby is pale, and all that (background talk) the baby go home, the baby if fine, most of the time they are able to recover nicely. But then when there is brain damage, to some extent, there is saw to the brain. That’s when as they grow, the body grow nicely but their ideological function becomes blur. So that’s our greatest challenge, our greatest fear. Those are the things that we really want to revert.

I: How do you think the healthcare system will respond to their needs?

P: How will it respond to their needs?

I: mhm

P: erm in our setting, what we do is that we: some of them when we follow them up and we realize that there’s a lot of delay in their ideological, we then transfer to the ideological clinic. Where they are continually followed on so that’s how come we try to help them even in their area of challenge. And apart from that, if they have any auto dysfunction too, then the physiotherapist will helps them. So that’s how we respond to their needs although it’s not 100% efficient, there are lapses because some as I said, you may lose some the mothers to follow-up. Some of the mothers will come in very late. Years after, because they think that yes because when things a are bit someway, they have a lot cultural believes surrounding them so some of them will try a lot of traditional medicine, herbal preparations and all that. Before eventually the child is brought to you, let’s say at age 3 years, age 5 years, the child is still unable to walk, the child is unable to talk and all those things. Then it makes it quite challenging for us to come in because we know that when we pick them up early, then we are able to help them early. Because if they pick them up early, you can see a let’s say speech therapist, physiotherapist and all that then we are able to help them. But if you see them let’s say age 5, he has develop some fractures because the baby is really walking well. It becomes very difficult because we may even need surgical repairs before the baby is able to walk; the child is able to walk well. So we have a lot challenges, but then we have a system in place which is not I will say 100% efficient. But there is a system in place so that if the mothers avail themselves for follow up, we will able to help these babies.

I: Ok so do you have any other comments about babies who look like they were dying, but survived or ill babies in the NICU that should make it, that should be helpful for us, in doing this research?

P: What I will say is that for us to really tackle these issues, then we have to start educating mothers right from the antenatal period. There has to be a lot of education, because if the mother herself is equipped with the knowledge, even if she finds herself in a situation whereby there was some delay along the way, she will: because she is educated, she will be able to say that no as for this one: sometimes let’s say this baby is not feeding well, there is some signs of the baby is not well. If the mother is aware that if you see this and that is delaying, it means that the baby is not well, it’s not doing so well so take the baby to the hospital. If the mother knows that, even if she discharged home, and nothing was said about the baby and the baby is discharged home, maybe nothing was said about the baby: the mother will herself be able to walk in… Because in our mother-baby unit, it’s a walk-in, you can walk-in and say that ah this my baby, doctor look at her for me. I think something is not right, you understand. So I think there should be a lot of education for these mothers. So that they themselves, and if they are educated, a lot of these cultural believes that they will be able to discard. If they know that this and that is a condition that can happen in babies, so if am seeing it in my baby, then I have to take my baby to the hospital. Then they can discard a lot of cultural believes. But if they don’t know anything, then the grandmother will come, then the in-law will come and say all sort of things. Oh this baby is suffering from this and it’s all because of this asra or somebody said something, or some people eye the baby and all those things. That’s why we have a lot of diseases, but if you know that this that is happening to my baby is a medical condition and so I have to seek medical attention then you bring the baby earlier, we can help her and reduce the mortalities or near MISS situations.

I: Ok, thank you again for your time and answering our questions. We hope your answers will help us understand more about why babies that seemed they would die, live instead. Please let me know if you have any questions?

P: oh no

I: Ok and if you do, I can be reached through Dr. \_\_\_\_\_, yea.

P: Ok thank you very much.

END OF INTERVIEW

Type: HCP Interview-KB9000

Date: 22-6-15

Position: Doctor-Junior Specialist

I: So…ok so, thank you so much for taking the time to schedule this interview with me today.

And so, as I’m sure Dr. \_\_\_\_\_\_ told you we’re trying to learn more about babies who have life threatening complications during and after delivery, um but who survive. And your thoughts and opinions about why some babies survive while others die are very important to helping us understand these issues better. Uhh, so as a reminder, I will be recording our interview. This is just so that I have something to help me remember what we talked about. Um it also means that I won’t have to take as many notes, I will just be taking notes on things I’m trying to follow up on.

P: Oh ok.

I: Uhh so, just so you know, the recordings will never be played public publicly. We will transcribe them and then destroy the actual recording. Uhh, if there is anything that you don’t want to talk about, please let me know. Also, we can stop the interview at any time. Please let me know if you would like to stop.

P: Ok.

I: Uhhh and what we talk about will remain confidential. And I won’t share the details with patients or others at the hospital. You will not be named in anything that is written about this research.

P: Oh ok.

I: And just for the recording I’m going to say this is KB9000.

P: Ok.

I: Uh ok. So we would like to learn more about your experiences with babies who are ill and their outcomes. You’ve been working on this for the NICU for some time now. \_\_\_\_\_\_\_\_ . Uh some of the babies had severe complications. Some of them, you may have struggled with and they died. Some of them, you may have struggled with and they lived. Some died no matter what you did. Uh some lived when you thought that they should not have. Um what do you think was the difference between those who lived and those who died?

P: Hmm… wow, ok. Emm so first of all, this is a teaching hospital I’m sure you are aware but this is a teaching hospital so we get about 80% of our babies actually coming in from the labor ward and then about 20% coming out from outside \_\_\_\_\_\_\_. Now number one, I’m sure, I don’t know whether you know that most of our admissions are like preterm babies, and then um asphyxiated babies as well as umm babies who have infections. So these are the major categories of babies that are admitted. Now in terms of those who die and then those who survive especially for babies coming in from outside this hospital I think it has to do with the timely referrals ok. Because you may have asphyxiated babies who are sort of you know rushed just in from the labor ward. They are quite bad but because they are sort of resuscitated, well-resuscitated in the labor ward. So that is number one, good resuscitation and then timely referral because if you have a baby who was, for example, transported over a long period of time from the periphery, for example, and brought, eh dey baby gets here like after a very long period of time, then they are further compromised. So even though you may have expected them to survive but because of the long travel time you know they they take to get here they are affected in eh in some way by the time they get here and may not be able to make it. Em like comparing it to someone who was just maybe referred from our labor ward straight into uh NICU. So that one factor, and then also the mode of transportation. People, babies are not transported under optimal [cutout-3:38]. Instead of, for example, transporting a baby in a transport incubator, for example, you have babies who are just covered in a cotton cloth or linen cloth and then just transported to NICU without oxygen, without IV fluids and things like that. So all these sort of influence em you know, your chances of surviving or not surviving. Mhmm yeah. So we talked about, resuscitation, timely referrals and then transportation and the optimum conditions. Yea.

I: Umm, so you said like time is a factor, what would you say really ends up increasing the amount of time that it takes for the babies to get here that are coming from the outside?

P: So the earlier the better, I really don’t have any time frame or time lines in my mind. But I mean if you are able to refer your baby as soon as possible and they get here in time, within the shortest possible time, say within 10,15 minutes they are here from the labor ward. I think it does a lot of good for the babies. Instead of them traveling over hours. We have babies coming from \_\_\_\_\_ for example, it takes about 2,3 hours for them to get here and that’s ehh really bad it really affects outcomes. Yeah. Mm.

I: Um so can you tell me um about the experience with babies who lived when you thought they were going to die? Um which diseases or conditions did these babies have?

P: So for emmm some of our for some of our asphyxiated babies for example, em there are some of them who are so ill so bad that you think that em you will think that em they are going to die but then em somehow they pull through. So that’s one, the asphyxiated babies and then again in this unit we have em issues with supportin’ extreme preterms for example. Em we are not able to offer like ventilation, you know support, uh blood pressure with inotropes and things like that and then we have challenges with feeding. So you may have tiny preterms coming in you think that oh this one may not be able to make it but somehow some of them are able to pull through. I have one there right now who is about 600 grams and you know she was written off very very first day that she came here. They were like, ‘oh this one.’ But she has been here for about two weeks and counting. She is actually quite well you know so yeah. These are some of the cases yeah.

I: Um and so… would you say, are is there special care that is given after the disease has been resolved or like whatever condition they had, after it has been resolved?

P: Mhmm, so after they have been discharged from the NICU you mean?

I: Mhmmm (/yes/)

P: Yes, ok, so from after after they have been discharged from the NICU, for all em preterm babies we continue to follow up at our NICU clinic. In fact even before they leave our NICU, we are practicing what is called the kangaroo mother care for them. So they stay in here and uh stay in with their mom. Moms are tying them on their chest so they are able to maintain their body temperature. Mom is confident with feeding and all that before she goes home. And once they get home as well we continue to follow them up at the NICU clinic where we make sure that they are growing, they are getting their vaccinations, and things like that. And then same for the asphyxiated babies, once we discharge them, we do not leave them to go, we continue to follow them up at the clinic. We expect, I mean there are some of them who will develop some sequelae after they have been discharged and so once they are discharged we follow them up, make sure they are not developing the sequelae like maybe hearing impairment, visual problems, you know cerebral palsy and things like that. So we follow them up at the clinic some of them will develop seizures chronic like, continuous seizures even after we discharge them. So we make sure that we are following them at the clinic, making sure that we sort of eh, look out for all these problems actively. If they don’t have all the better, but if they do have or that we think they are developing we refer them to the appropriate ehm specialist who deal with all these problems and then they take over. So for example, we refer them to the ophthalmologist, we also refer them to have a hearing assessment done and then we refer them for physiotherapy because some of them become so spastic that you have to release all the you know spasticity and all that yeah.

I: So when they are coming to get follow-ups do they see the doctors they saw on the NICU or is it…

P: Yes, so its it is teamwork. Ok so on the clinic days some of us will be at the clinic not everybody on the unit is at the clinic but we do it in such a way that we all rotate through the clinic. So they may not see the doctor who actually did all the work whiles they were on admission or you may be lucky enough to meet the same doctor eh huh. But we sort of is the same NICU doctors who see them at the clinic mhmm.

I: Ok. Um, so what instructions do you feel like mothers are getting for caring for their babies if they ended up living when they almost died?

P: Hmm, also, ok, let me give an example for some of our babies with congenital anomalies. You know we have babies with congenital anomalies. Mothers come, some of them may not actually have expected ehm that they would have a baby with multiple anomalies and things so some of them would actually want to leave the baby, and especially when they see that the baby is really not pulling through ok. But ehm, we as doctors will, most of the time, try to encourage them you know to stay on. Ehm we don’t have the benefit say, diagnosing congenital anomalies sometimes, right from the beginning, but we can actually see that oh this baby has that and that anomaly. Eh and so we are able to tell them, ‘Well your baby has a problem. We don’t really know exactly what the problem is, but maybe has this that and that, and we are hoping to do maybe this investigation and that investigation, we have to put things together.’ Some of them would want to leave even after you have told them all that but sometimes you tell them hey you never know what is going to happen to your baby. It looks like baby is not making it but we take one day at a time and then we do our best to you know make sure that we are offering everything that we can for the baby. We really don’t have the luxury of offering everything as we should. But we are able to do certain things. And some of the mothers will actually understand you and would want to see, stay on as you tell them you are taking one day at a time. Some of them are also happy that at least you are doing something for their child, like doing investigations and X-ray here and ECG there and things like that so yeah. We try to take them along as we go yeah and not leave them in the dark.

I: And so like, let’s say after the baby is discharged, do the mothers get special instructions for taking care of their baby since they you know kinda had a life-threatening event?

P: Mmm so, em, well o, any, for any discharge from the NICU, we make sure that we give you some discharge instructions before you go home. When have special problems ehm we tend to take you on the one on one basis and tell you what’s the plan, you know, planned reviews, for example, ehh so that I mean if you need to see ehm a plastic surgeon after discharge we make sure that we do all those arrangements for you before you leave the hospital. If your baby for example requires special feeding we try to do all that for you before go home. We do that kind of feeding before you go home. Things like that, yeah. So we also take them through the routine things that we expect them to do like, making sure you are feeding, immunizations, medications, and things like that. We give them all that talk before they leave.

I: Um, so have you ever discussed one of these cases of babies that survive when you thought they shouldn’t have with your supervisor or with coworkers?

P: Uh… well we we I don’t think that we’ve had like eh…like a formal meeting where we go like ok maybe this baby should have, well this baby really we were not expecting the baby to die but the baby survived and so maybe what did we do, what didn’t we do right, and things like that. We (sucks teeth) I don’t know, we really haven’t had any discussions (sucks teeth) I can’t remember any right now but we sort of, we discuss cases everyday ok. Everyday, I mean we have our ward rounds every single day, we have ward rounds moving from baby to baby eh huh. And so we discuss babies, mm as we go along but I don’t think we have made it a formal session saying that oh this baby could have died I mean, how come this baby made it, what did we do right oh I don’t think we have done anything like that before mhmm.

I: Ok umm, ok so but you said you do discuss like during rounds umm or like amongst your team umm and so when you discuss it what is usually the reason why you’re even discussing the baby?

P: Ok, so I mean with the supervisory bit that you chipped in, so there’s the hierarchy in the unit too. I mean I have someone who is above me, ehm I have a consultant for example this morning she was here and I had a challenge with a particular baby and so I sort of ehh I mean I presented the case to her, give her what I thought about the case, she also gave her opinion and then we try to find the best way forward for that particular baby, that’s a very very sick baby, that we’ve been battling with for over the past about one week now and so we had to ehm find ehhh way of moving forward from where we are right now. So it’s more of like a discussion and then trying to find what is best for the baby. I also supervise junior colleagues and they also come to me er oh during the rounds you tend to you know let them present, you ask them questions about the baby and its all in a bit to do what’s best for the baby. So just to get to know the baby more and to find a way of doing something yeah, better for the baby, mhmm.

I: Umm, so would you, have you ever received formal training on how to handle these kinds of cases, like of babies that looked like they were gonna die but did not?

P: Uh, formal training (laughs) formal training well I don’t think its, should I say its formal training? Ehm I think we tend to learn on the job a lot. Ehm you have experi-experience that’s one, and then you do your own little reading here and there, and you are also learning from others as well. So I, for example, I learn a lot from my consultant, I also do read a lot on my own and then I’ve been working for a while now so there are certain things that I know that I mean if you do in a certain way would be of much more benefit to the patient rather than doing it in another way. So not really, any formal training. Ehm, neonatal resuscitation, yes. Ok, let me say that neonatal resuscitation, I’ve gone through a lot of like neonatal resuscitation programs and those were like formal training, so in terms of resuscitation I would say yes. I would say I have received quite a number of ehm yea trainings in that aspect yea. Mhmm.

I: Ok. Um, do you think there should be more training on how to handle these kinds of cases?

P: Mmm, umm yes. Well so let me er again talking about neonatal resuscitation in our labor ward for example. Our midwives are very busy midwives and ehm sometimes we actually do the training, we offer the training. When I say we I’m talking about us in NICU and then the department of child health as a whole. We offer the resuscitation for the midwives in the labor ward. And well we are not able to do it as often as we should because number one they are busy we are also quite busy. And you know with resuscitation once you train you train once, if you don’t practice what you’ve been taught you tend to forget whatever you have been taught and then the next time you you are in situation where you are expected to perform you are not really performing right. So I think yes, we need train them over and over again not just one of training. But they also need to put into practice what they are taught. And so that would help. Infection prevention is another area that we could look at because I mean, clean delivery is important. And then you know ?(physicians)? in the hospital if you are not washing your hands properly and touching one baby…moving from one baby to the other. And these are all preter (/preterm/)—already at risk baby at a higher risk, so that is something we could look at. In the community ehm, because we tend to receive babies from off site, one thing that I find challenging is for them is the management of neonatal jaundice for example. We don’t get a lot of that from the community to this place but I have looked after babies in other like in ehm at the child health department, neonatal I’m talking about, from ehm the outside coming to the child health department for example. And these are babies who have had so I mean ehm levels of bilirubin that are so high that I mean they could kill the baby and this condition is highly preventable you can, yes babies who develop neonatal jaundice, for example. But if a midwife, for example, is able to detect neonatal jaundice very early he or she or she will be able to intervene quickly with phototherapy or refer quickly so it doesn’t have to become so bad before because a lot of them are referred already with encephalopathy and at that point, I mean when you even do a exchange transfusion, ehm the baby may survive but with sequelae like cerebral palsy and things like that. Mhmm. So yes I think that we need to educate more.

I: Um are there any other kinds of trainings that you feel like there should be more of?

P: We have another training that well we recently we actually did with our own nurses in the NICU. That’s essential care for every newborn baby. So we taught them how to do basic things like you know you know infection prevention is one, keeping your baby warm is one, feeding your baby, cord care, eye care, and things like that. So yea they are helpful. Yeah.

I: So for that one you trained the nurses?

P: Yes.

I: So so they could be able to tell the mothers? Or just so the nurses…

P: So they are able, we train them so that they apply what they apply what they’ve learned and then when they are discharging the mothers they teach the mothers how to do that, all that. Mhmm.

I: Ok. Um, what do you believe is the most important thing to understand in order to handle these kinds of babies that lived even though they seemed like they were going to die?

P: …Understand in terms of…?

I: Just understand about their care overall.

P: In NICU?

I: Mhmm (nods yes)

P: Mhmm…Well, so I think that I mean as doctors and nurses ehm taking care of ehm sometimes ehm when they come to you the diagnosis, for example, may not be clear cut. But ehm one thing that I realize is a big challenge for us here is, for example, monitoring of the babies vital vitals like the temperature, respirations, heart rate, ehm getting the oxygen saturations and things like, these are simple simple things that you can do because if a baby is going to die, for example, I mean if you are really monitoring, for example, your heart rate, respiration rate and things like that you would pick up something at some point that would tell you that this baby is not doing very well and so you need to keep an eye on the baby. Unfortunately we don’t have monitors and so we have to do a lot of these things ourselves. So recently we found a baby who was apneic, a premature baby I mean who already has risk of being premature. Ehm we found out the baby was ?(apeneing)?, just laying there not breathing. And so you stimulate the baby and then baby starts breathing again, but if this baby for example was hooked onto a monitor, maybe the monitor’s tone would have shown that there was a problem or if there was like an apnea monitor, for example, the apnea monitor would start ringing the bell telling you that hey baby has stopped breathing. So it requires that we are all vigilant and that we do the simple things like making sure that we are taking our vitals properly. That’s important I think, yeah.

I: Ok. And so just like you said like these are things important to understand in the NICU, what will you say are the most important things to under (/understand/)—for mothers to understand once the baby has been discharged?

P: I didn’t get it properly.

I: Um like what do you believe is the most important thing for mothers to understand once they have their baby um, that almost didn’t survive [crosstalk].

P: Mhhm, ehh… so I, I, I think that once they have been in NICU we’ve sort of you know been telling them what has been going on in NICU. So once they are going home, well we need to tell them if we think that there are any complications that may have arisen from the condition of the baby, whatever condition. I think we need to let them know about whatever. First of all, we reinforce why the baby was admitted to NICU and then tell them of the complications that we expect the baby will have and then also make sure that we tell them that we, about the need to follow up and all that. So yeah these are some of the things that we ehm, this kind of information should be given to the mother at the time we are discharging before they leave for the house, yeah.

I: Ok. Um are you familiar with the term near miss?

P: Emm, well I’ve heard near miss before ehm think I’ve even read about something. But let me try and see if I can remember (laughs). Well so a near miss is like ehm so it’s like ehm maybe you are expectin’ that a baby will you are expectin’ that a baby or a patient would die ehm but ehm let me come again. (laughs) So maybe there’s a risk factor. Ok let me use a baby. So for a baby ehm maybe a certain risk factor in the mother that makes the baby at risk of dying but then somehow the baby makes it or something like that.

I: Mhmm.

P: Yeah.

I: Mhmm.

P: So, that what I can well remember.

I: Yeah, I mean yeah that’s basically what we have been talking about [crosstalk]. Basically when it looks like

P: The baby is going to die.

I: Mhmm but they live.

P: Yeah.

I: Yeah. Umm, do you think like all providers so like doctors, nurses, or whoever is like really dealing with the babies have like the same idea of what a near miss is?

P: Hmmm, umm…I think it depends on the category of health care worker that we are dealing with. So for doctors and maybe senior nurses, yes, they may ehm, well they may be able to, for example, identify a baby who is for example at risk of dying, ok. But if you say have ehm a health care assistant, for example, ehm who is taking care of a baby who has been referred from the labor ward, he or she may not really understand the gravity of ehm whatever is going on and may have you know a leisure attitude towards what he or she is dealing with, ok. So, for example, I mean, sometime, I can’t remember the exact time, but there was a baby who was brought in from the labor ward ehm by I think a health care (changed from “nurse”) assistant or an enrolled nurse. I’m not too sure about the category of health care worker but she came in, baby was so asphyxiated. She had wrapped the baby and she just walked into you know NICU holding the baby and was like ok I have brought a baby in and she was standing there. For somebody who really understands what was going on, will be very aggressive at you know to the reception nurse, I have a baby, this baby needs attention can you please stop and come and see my baby and things like that. But she was standing there and you know this place is very busy and so the nurse who sees her standing there she was like ok I am coming. By the time we opened up the cloth covering the baby the baby was all blue and gasping and all that so we quickly had to take the baby inside and start some resuscitation for the baby. So I think of health care worker, even for doctors, some of the junior doctors, for example, who are who have just started housemanship may not be able to distinguish a baby who need immediate attention from someone who can oh quietly lie down for a while, while I sort out the other person with more pressing needs, mhm yeah.

I: Um so do you think it’s like the distinction of a baby being near miss or not do you think that distinction is useful? As a health care worker?

P: Yea, I think so because it makes you more alert so you are actually watching out for that particular baby. You want to do everything you can for that baby, of course we do everything that we can for every baby but some babies are more ehm like in need, if I should put it that way, than others. There are others who can wait, especially looking at the workload that we have, there are others who can wait and there are others that you need to attend to immediately so that you know you do not end up losing them ok. It has happened a few times where you think maybe this baby you know because the way you are doing things in on some other baby you turn back and then you realize that this baby is already gone. So er the fact that we can classify a baby as a near miss needing a lot of attention can help us in our day-to-day work so that we’ve sort of take care of those who really need our attention, you know, earlier than those who can actually wait a bit, yeah.

I: Um, if you knew a baby was classified as near, as having a near miss you think it would change how you managed that baby?

P: Yes, I, it would. It would because I mean, fine, that baby em is already at risk and it tells me if I don’t pay close attention to that baby I might actually lose the baby so yes it it would. It would affect my way of approaching that baby and taking care of that baby, yeah.

I: Umm and so what challenges do you think babies who experienced a near miss will face as they age?

P: Ehm, hmmm so from what we have been talking about so far, so, for example, if we take a asphyxiated baby, for example, ehm one of the big problems that I see is like the cerebral palsies that they develop as they grow, some of them develop seizures as they grow and then for our preterms, some you know, some end up bleeding into their brains and all that and so they may end up full of a lot of fluid that they may have to get drained ehm yeah, things, things like that. So the cerebral palsies they are very real for us in this NICU because as I said a lot of our babies are asphyxiated babies and we tend to refer a lot of them to the neuro clinic because they have developed either cerebral palsy or they continue to have seizures despite ehm whatever ehm their treatment and all that yeah.

I: Um, and so… how do you feel like the healthcare system responds to these babies needs as they age?

P: How the healthcare system responds to these babies? Ehm I, I, I think that well we are still in the era of trying to develop like programs for such such babies. Ehm we don’t have well like laid out um protocols. For example, when you go to a district hospital ehm district hospitals may not have the capacity to look after some of these babies. You may find something put down in the original hospital. For example, I worked in a regional hospital before and there was no intervention, for example, for babies who had cerebral palsy and so it was only when I got there that I had to put something together for babies or children who has cerebral palsy you know you need to refer them for physiotherapy, you need a nutritionist to come in or a dietician to come in to help with their feeding because some of them will have feeding difficulties and things like that mhmm. So the regional hospitals, depending on whether you have a pediatrician or not, may not have a program for some of these babies. In the teaching hospitals, yes because we are more or less like a specialist hospital with different specialties we tend to have some of these programs eh running. So, for example, for us at child health we have a neurodevelopmental clinic for our cerebral palsy patients, ehm who you know come about as a result of severe birth asphyxiates. And then for some of our preterm babies and then we also have the physiotherapy unit that helps with you know with helping with all their spasticity and all that to help relieve the spasticity. We have a dietician who helps with managing their nutritional needs and things like that. So yes we have some programs or protocols in place under the teaching hospital but outside the teaching hospital, I must say, it’s a big challenge because the Ghana Health Service doesn’t really have like laid down ehm protocols and policies for babies or children ehm who come out of a near miss.

I: Ok. Umm well those are end that’s the end of my questions unless you have any other comments you want to make about what you typically see for these babies in the NICU that you think would be important for the study.

P: Mhmm…well so I think one comment that I’ll make in everything that I have said is that ehm yes I think we always want to um do every possible like I mean like, I mentioned the monitoring of vitals, um is one area that is very dear to my heart like measuring the babies temperature, respiratory rate, heart rate, oxygen saturation. It is so dear to my heart, but it is the workload that ehm that really affects what we can do. You have a cubicle that has about 30 babies and you have one or two nurses. This is a NICU, it’s suppose to be a neonatal intensive care unit. But I don’t think we are offering that kind of ehm intensive care that our babies need, mkay. So yes we are doing our best but I think we are so challenged when it comes to human resources and it’s actually a reflection. A lot of these near misses are a reflection of what is actually happen in terms of NICU human resources and ehm maybe equipment challenges and things like that. Because if you have a midwife who has to take care of how many women in labor, I mean you can just imagine how effective her monitoring is of the labor that’s you know, the woman is going through. So again the baby comes out already compromised and then comes here and again we come to meet other babies so many other babies in one cubicle and you don’t have that attention that you need to ehm get the best of care. So so that’s probably what I will add to to to the study. I think there are human resource challenges and I think the near misses are actually a reflection of what is really happening here in terms of human resources.

I: Well thank you so much for your time and answering the questions. We hope your answers really help us understand more about why babies that seem to like they were going to die, live instead so we can help more babies live instead. Uh do you have any questions about the study?

P: Ummm…not really. I see Dr. \_\_\_\_\_\_ around all the time. If I have any questions I will ask him.

I: Yeah, you should ask him, um also you can ask me, I mean I can give you my email address or you can talk to him if you have any questions.

P: Ok, ok, alright.

I: Alright, thank you so much again. I will stop it now.

P: Yeah.

END OF INTERVIEW

Type: HCP Interview-KA9008

Date: 30-09-2015

Position: House Officer

I: Ok alright, thank you for taking the time out of your busy schedule to meet with me today. Uh so, this project is focused on learning more about babies who have life threatening complications during and after delivery, but who survive. Your thoughts and opinions about why some babies survive while others die are very important to helping us understand these issues better. Uhh, so I will be recording the interview. This is just so that I have something to help me remember what we talked about. I also will have to take as many notes, more so just notes on stuff to follow up on. Just so you know, the recordings will never be played publicly. We will transcribe them and then destroy the tapes. If there is anything that you don’t want to talk about, please let me know. Also, we can stop the interview at any time. Please let me know if you would like to stop. What we talk about will remain confidential. I won’t share the details with patients or others at the hospital. You will not be named in anything that is written about the research. And just so the recording knows this is interview KA9003. Um, what we would like to learn more about your experiences with babies who are ill and their outcomes. You’ve been working on the NICU for some time now. Some of the babies have had severe complications. Some of them, you may have struggled with and they died. Some of them, you may have struggled with and they lived. Some died no matter what you did. Some lived when you thought that they will not live. What do you think was the difference between those who lived and those who died?

P: Ok first all of all, I think like you said earlier it depends on the presentation. As in the clinical presentation that comes on board and also the time that the patient was brought. Most of our patients who come from the theatre that’s from the delivery ward they survive yes. Because most of them come from prematurity, respiratory distress secondary to prematurity, those also coming from our vicinity as in the hospital with neonatal jaundice usually survive because they are picked up early and then we are able start the phototherapy. But for patients coming from the house or from other hospitals, especially with this neonatal jaundice, some of them end up passing away. Some can be saved, depending on the timing and then in the end, nothing much can be done about it. We start the photo: we start the exchange, they die half way through or we finish the exchange and they still not make it.

I: Can you tell me more about your experiences with those babies who lived when you thought they were going to die? Which diseases or conditions make these babies die?

P: Personally I think birth asphyxia yea, for my experience, they were the ones I thought might end up passing away but didn’t pass away. Those coming with (background noise) birth asphyxia most of these ones usually are coming as a result of the delivery process. Some come with severe asphyxia and then eventually it’s resolved. Some come and it doesn’t resolve, but most of the time, those are the cases that I thought the babies were going to die but they ended up making it.

I: And why was it usually not resolved?

P: It resolves with time, when it doesn’t resolve, I don’t know, I guess perhaps the condition would have gone on for long. And then some acute problems with perfusion to the vital organ, so then most of the vital organs will be delayed. The heart, the brain and then whilst in, then the patient will be good for that. Even they go, I’m sure later they can they end up with some form of (inaudible)

I: Is any other special care given after the case is resolved?

P: Yea, they start physiotherapy, and sometimes you pick up increase tone, you know tone right, yes fastacy in the muscles. So when that happens, you are thinking about possible therapy so you need physiotherapy to avenge some these issues. And I think the prematurity; the preterm babies also make it a lot over here. They deliver a lot of them and because of this special ward we have for such babies, much attention is given to them: the immediate is given to them and they survive. (background noise)

I: so let’s get on, are mothers typically given special instructions for caring for babies that lived but you thought were going to die?

P: Erm personally, I haven’t given any advice but then reviews are review babies are given and they go to see the higher specialist and consults so I’m sure they talk to them.

I: Do you feel like the mothers usually understand any instructions that are given to them?

P: not really, even on the ward, you give them instructions and they don’t seem to want to comply. And I think they do not understand, most of the educated mothers understand what we say. But I think majority of our population are illiterate so they don’t really get what we’re trying to tell them. Some of them just want to go home, some actually think we are just keeping them here and they keep worrying you about wanting to go home. They are quite difficult.

I: So when mums don’t follow like the instructions you give, what is usually the reason why?

P: Some mothers, I remembered I had a patient whose baby had neonatal sepsis, I think the temperature wasn’t resolving. It was this funny temperature pattern, going high and then coming low, episodes of hypothermia and hyperthermia. And she kept saying that she wanted to go home because her mother had died. We tried everything to explain to her that the baby wasn’t stable, but she didn’t listen. And in the end, she took the baby and tried to run away, she was brought back by the security and we had to write out something for her straight home and then we ended up knowing the baby on oral antibiotics. Hopefully it will resolve but we don’t know what is going to happen to the baby because the baby wasn’t with us.

I: Ok, so like is there any cultural barriers that prevent mothers from understanding?

P: Yea a lot, even with this neonatal Jaundice that we are trying to educate the mothers about. I don’t know what goes on at the ANC, well I think they do their parts but most of the mothers don’t go anywhere. They have this cultural I think they say you keep the baby indoors for 8 days. So most of the mothers keep the babies indoors, they don’t bring the babies out. And then by the 8th day when the baby is ready to be brought out, they realize the baby is so yellow. They come to the hospital and they would already have developed some bilirubin encephalopathy. I just about 3 days ago, I say a couple of patients who had things on their cot

I: some had what?

P: who had some had hair, some had pepsodent: tooth paste on their cot, their umbilical stamp and I don’t know where this is coming from. I don’t know if t’s a cultural practice but it looks like something they do at home. Yes most of their uneducated mothers, perhaps they want the cot to be called off very fast: so they end up putting something that is a bit matte on the cot. They end up coming with cot sepsis, if education will go on it will really help.

I: Do you feel like there is some training I mean from the mothers end, do you go to ANC and you feel like is some education about not putting stuffs on the cot.

P: Yes there is, I heard recently that the mothers they are told the dates for education and the dates for clinical work, so most them end up going for the clinical. When they know that today, maybe Monday is supposed is supposed to be for education they wouldn’t turn up. But Tuesday the doctor is coming or the midwife is coming, that’s the day they will go so most of them are quite ignorant about most of the neonatal conditions yea. They take a number of them to lose to about 2 or 3 babies before they become quite conscious. I remember we had this patient that we kept here just because she has had 3 previous neonatal deaths from neonatal jaundice. Then when she delivered the 4th she brought the baby herself that she want it to be kept here and monitored just so the baby won’t develop neonatal jaundice.

I: so it’s like how the baby (inaudible)

P: yea

I: Have you ever discussed one of these cases of babies that survived that you thought they should have died with your supervisors or coworker?

P: Erm coworkers yes, supervisors: I think s but I don’t really remember, we didn’t talk about the cases. I don’t remember extensive sort of like a formal one like we are doing, but we talk about it. Those who survive when we thought they wouldn’t and those who pass away when we thought they would have survived.

I: Ok and so what is usually the outcome of the discussion?

P: I think it’s usually: erm one in the interest of the patient and also in our interest. So that it will help you to practice better. You know the mistakes you committed and then you learn from your mistakes and then I guess you come to the realization that every patient is desperate yea. We can’t possibly expect the same outcome for everybody because they presented same issue.

I: Have you ever received formal training on how to handle these cases of babies that survived when you thought they would have died?

P: formal training, how do you mean?

I: just a training that will specifically give, it could have been in school or even by the hospital

P: We have morning meeting every day and I think they are educational sessions. So for instance for Mondays we have emergency: Mondays are for emergency: we take emergency from MBU that’s the neonatal unit, and then PEE, the pediatric emergency and we take challenging cases and discuss them. And then we learn from the management and how the cases went, they’ll show new principles and new methods to approach so we can learn.

I: And do you think there should be more training on how to handle these kinds’ cases?

P: we would always ask for more we are doing very well but there is the need

I: what kind of training so you think they should add?

P: to us?

I: to handle these kinds of cases for the babies?

P: I think most importantly what I I’m quite passionate about is from the mother’s level from the ANC. I really don’t know how we are going put it do them: my project in school was about neonatal mortality yea. And with this same issue that we are talking about. And I think when I went to the village, what I think that was this same thing we are talking about, they don’t go for the ANC. And even for those who go, they just go because they want to see the doctor. So perhaps if they are not going to listen to us during the educational section then maybe the doctor could take it up. We will plead with the doctors to take it up during their examinations, talk to the mothers about these conditions. It’s not so few people because we have a lot of patients and the doctor patient ratio in Ghana is outrageous. If you’re going get time to talk to every single patient about neonatal complications, pregnancy complications and the outcomes; it’s going to be a lot of work as a healthcare. I don’t know consulting in the consulting rooms would have been the best. But as I said earlier, the patient doctor queue will be for hours.

I: Ok what do you believe is the most important things understanding in order to handle these cases?

P: The most important things to understand, education, I think if more of the mothers are educated, they will come to understand what we are saying more. Because from experience, it looks like your communication is much easier with the educated mothers than the uneducated, so I think education is ok.

I: Are you familiar with the term near MISS?

P: neo MISS

I: Near Miss yea, you know what near MISS means?

P: I just read it from your sheet that you gave me, other than that, I didn’t know anything about it. But I’ve seen your people here a couple of times, they get information from the patients, I think they told me about it some time, but I just wasn’t listening yea.

I: ok so near MISS is when erm a baby or a mum so let’s say neonatal near MISS, a baby looks like it’s not gonna make it but it does. So that like a near MISS, you nearly missed them

P: oh ok

I: Do you think having that <cross talk>

P: near MISS!

I: yea

P: oh ok (laughter)

I: you think I said something else?

P: I heard neo MISS

I: oh sorry erm do you think having that distinction of a baby that had near MISS first and foremost did it in school as a healthcare worker?

P: yea I think it we need to learn, we learn a lot from these babies and from the mummies and then we pass it on to other babies. Maybe it is something wrong, stop those that the baby wrong going

I: So if you know a baby was classified as having a near MISS do you think it would change how you manage that baby?

P: If I knew the baby had been classified so the eventually survived, would it change…

I: how you management that baby?

P: well I I’m quite personal with all my patients so inasmuch as I would have treated this patient with care, I think I would do that to all my other patients. I feel bad when I lose a patient in my shift. They are all: when I I’m taking care of them so I think it will be (background noise)

I: What challenges do you think babies who experience the near MISS will face as they age?

P: Mmm it all depends on the outcome of management, so that if because near MISS with neonatal jaundice that eventually survived developing no severe complications like this bilirubin encephalopathy. If babies are not going to end up developing any major complications like cerebral hole they’ll grow up you and I and nobody will ever know that something like that happened. And I think I remember my mummy telling me some time ago that when she gave birth to me, they said I had asphyxia. She couldn’t pronounce the term well but after my fifth year, I realized that was what she was talking about. Because it was breach and she claims I came and I hadn’t cried for so long and she stayed at the hospital for like 2 weeks, that’s what she told me yea. Right now am grown, I’m ok I and I don’t anybody will look at me and think I had asphyxia, and so I don’t think there is really you will know from them growing up, unless some severe complication occurred. But if nothing like that happened, you can’t really tell they are all fit. (Background noise)

I: Do you feel like the healthcare is able to respond to the needs of babies that do have complications as they get older? (Background noise)

P: Are they able to respond to health needs, actually probably they are doing their best in Ghana, that is not the best compared to place like UK and that will be partly because of infrastructure, and what they say and then human resource, I think they are not enough

I: What particular resources do you feel are lacking for the kinds of complications that ….?

P: I think for instance right now for about 3 days now I am taking care of the phototherapy unit right now. And I’ve been complaining because we put the babies under the blue light, the blue lights it’s almost faded away. I’m sure it’s been there for years and now this is my second month in MBU as I told you. I have been here in April and it wasn’t like this they were quite intense. But now, they are so shallowed but it’s not as bright as it used to be. So you put the babies under it and then you come the next day and they are lower than they were the day before. Yea this could end up: I don’t know, so far we haven’t had any bad case. But I’m sure in days to come if they are changed, it will be a cos 90 work of the (inaudible) hoping they wouldn’t want record patients dying in the hospital before they change the phototherapy machines. So recently stocks (inaudible) (background noise)

I: Ok so you have any comments about babies who are severely ill that you though they are not going to make it that they survived that you wanna tell us in order to help us with this study, any comments or about ill babies here and then surviving? (background noise)

P: to help you with you study or to help you with the patients? (background noise)

I: to help us with the study

P: nothing much is coming to mind, nothing much is coming to mind

I: well that’s fine, well thank you again for your time and for answering our questions. We hope your answers will help us understand more about why babies that seem they would have died live instead. Please let me know if you have any questions?

P: I’m just knowing in the end you will help, well afterwards you put up the data that you got, you will tell us the outcome or what will you do for Ghana after your study?

I: Well this research, this study is only going on in Ghana and so: it going in 3 different places so the main leaders are their sites depending on if we find something useful, I am sure they intend to share the data with you all so like to a day to record if there is something useful and kind of depends on what we find.

P: You are thinking if you make the information disseminated very well so that everybody has it from government to healthcare, like everybody the seniors, it will help increase our level of involvement with the patient life. That’s during pregnancy, and perhaps better our ANC system. Because I think seriously that’s where I have a problem, so if there better education of all females and then better ANC provision. (background noise)

I: Ok well if you have any questions in the future, I can be reached through Dr. \_\_\_\_\_ or you can also ask Dr. \_\_\_\_\_

P: can I have your contact so anytime

I: Ok thank you

END OF INTERVIEW (the background was too noisy from 16 minutes to the end.)

Type: HCP Interview-CC9017

Date: 22-7-15

Position: Doctor-House Officer

I: Alright. Thank you for taking the time out of your schedule to meet with me today. As you may know, this project is focused on learning more about babies who have life threatening complications during and after delivery, but who survive. Your thoughts and opinions about why some babies survive while others die are very important to helping us understand these issues better. As a reminder, I will be recording the interview. This is just so that (phone rings) I have something to help me remember what we talk about. It also means I won’t need to take a lot of notes, I’ll just write down what I would like to follow-up on. Just so you know, the recordings will never be played publicly. We will transcribe them and then destroy the tapes. If there is anything that you don’t want to talk about, please let me know. Also, we can stop the interview at any time. Please let me know if you would like to stop. What we talk about will remain confidential. I won’t share the details with patients or others at the hospital. You will not be named in anything that is written about this research. Also just so it is noted on the tape, this is interview CC9017. We would like to learn more about your experiences with babies who are ill and their outcomes. You’ve been working on this NICU for about \_\_\_\_\_\_\_\_ now. Some of the babies have had severe complications. Some of them, you may have struggled with and they lived. Some of them, you may have struggled with and they died. Some died no matter what you did. Some lived when you thought that they would’ve died. What do you think is the difference between those who lived and those who died?

P: Em, I think that eh one, our NICU is a little eh understaffed. That is the first thing uh huh. So ehm monitoring becomes a problem. Em we don’t have, let’s say, em the necessary em electronical electronics to, let’s say, put a child on a monitor and that’s you can just take a quick glance and then uh, let’s say, continue with your duties. Like you have the ECG machine reading, you have the pulse ox (/pulse oximeter/) and everything just there and then taking it in real time so if you are doing some you can just take a quick glance and then you see everything then you can continue and work. So you have to be taking, let’s say, the heart rates manually, have to check the SpO2 manually and all those things. And because we are quite understaffed, if you have a couple of critical em patients, paying attention to each child becomes a little difficult. So you’ve had circumstances where em maybe a child is going into hypoglycemia but the nurse is let’s it’s feeding time. So the nurse is feeding other children and then this child goes into hypo. By the time the nurse gets to the baby the baby would’ve passed anyway and at that point in time as a doctor you can do very little. So that is just em a (phone rings) hypothetical example, not something that happened before. So em yes one, understaffing; two, em our NICU is awfully inadequate in terms of equipment. Em we don’t have a respirator, em our incubators are limited, we don’t have a a our ?readings room? has broken down. So ehm managing preterms, if you have about three or four preterms coming at the same time who all need incubators space then it becomes a challenge. Em you might have to try sacrifice one for the other em depending on how good one is and how bad the other is uh huh. So those are clinical decisions. Em children who come in with high risk respiratory rates ehm, most of the time you if indicated you want to put them on a ventilator and give them the time to rest. Let the ventilator do the breathing for them, allows the body to heal and to be much more faster by it but we don’t have that. So children have to work em to breath and at the same time work to solve their own issues and that’s that’s another problem. So I think yeah, infrastructure, logistics, ehm personnel to em personnel. Well em I can’t say much for the doctors, I think as of now, our number is quite adequate for the number of babies that we have. Em we also don’t do things like em arterial blood gas, we don’t do em electrolyte checks, em just because our lab uh lab facility can’t run them. So babies who are becoming acidotic or (stutters) alkalotic you can’t really correct those things. Those who have electrolyte imbalance, I think we miss a lot of children through this, through that as well.

I: Mhmm.

P: Yeah.

I: Ok, um so what is the reason like the labs can’t run those tests? Just cause they don’t have the tests or…?

P: Um well first first of all, em you need to have the machine to run a lot of tests yeah. Um we have an arterial blood gas machine and it’s placed at the ICU. And for arterial blood gas you can’t just take one value and then use it to treat. You need to take series of em samples to know whether your management is working. And each costs about 60 Ghana Cedis for an arterial blood gas. Now if you if the minimum wage is about five cedis, 70 pesewas, translated into a month that should give you less than 100 cedis a month. So if you are telling somebody who is living on minimal wage to pay 60 cedis to do to do em an arterial blood gas that you have to do about three, four sometimes five, six times, it’s really kind of insensitive. So what’s you the doctor telling the patient to do something like that so you wouldn’t request for it in the first place. That 60 cedis may be used to buy drugs that the child may need uh huh. You just assume and then the child may need so that’s one challenge. Two, we don’t we don’t have the equipment. Yeah we don’t have the equipment. We we have a CPAP machine but the necessary things that we need to um that need to work with it we don’t have it so you can’t put two babies on a respirator. And those are the main things, and so its mostly the logistics.

I: Mhmm.

P: Yeah, mostly the logistics. And I’ll add space cause our NICU is quite small. And you um sometimes you can have 30 babies on admission. And that’s more space. So space um we don’t we don’t em, infection prevention it’s not the best comparing to international standards. It’s not the best but that’s what we have and that’s what we work with as well. So I think those are a couple of things.

I: Ok. Can you tell me more about your experiences with those babies who lived when you thought they were going to die? Which diseases or conditions did these babies have?

P: Um I think I think those ones maybe mo-mostly are premature babies. Yeah, they they sometimes they will look fine and then the next day and you come and then they are going down. Or you see them today, they don’t look too good, the next day you come and then they are doing quite well. It’s it is difficult to say because you don’t have the eh requisite monitoring tools uh huh. So it’s difficult to say. So maybe some of them you can attribute it to genetic make-up, maybe they are just genetically em fighters. Some children are actually fighters and we, in medicine, people you always tell people to hang on and I think that it is the same for babies. Some babies actually fight to stay alive but em it will be difficult to give a scientific reason as of now because we don’t have the necessary monitoring tools to say that, ok this baby was alkalotic or acidotic we did this this this and then the child has come out of it. And because of the acidosis the child was sick, now that the child is not acidotic the child is getting better. Or the child was on a respirator and the child wasn’t doing well before the respirator, put the child on the respirator, child is doing much much much better. So it is difficult to say, sometimes we only hope for the best actually. And I’m being quite frank that actually I hope for the best. You do what you can do and then hope for the best so it’s quite difficult to pinpoint that doing this, this, this. But the things we can deal with we readily deal with. So hypoglycemia, hypothermia, em infections, em we try and deal with infections really well. We have em good cover of antibiotics em I think our [inaudible-8:30] are really good. Some of the antibiotics [inaudible 8:33] are really good. So and then em the nurses they do their best, they feed when they have to. If you tell them don’t feed, they don’t feed. They they always wait for the doctor’s em em instruction before they do stuff. And some of them are really quite experienced. So they see a baby and then they draw your attention because they know this baby, let’s check this, let’s check this. And then you actually find out yeah, it’s this thing and its its it comes with years of experience, years of experience. Some of these em people started their em this training even before I was born, so when they talk you sometime, you have to listen to them, yeah.

I: Ok. So is any special care given after the disease or condition these babies may have is resolved?

P: Special care…Well I think em those those who need em special care in terms of feeding, the feeding issues are addressed. Those who need special care in terms of em supplements, in terms of em multivitamin, iron, calcium, those needs are addressed. Em I don’t know if em towards discharge we normally see a sick babies earlier, those who are really sick. We normally won’t see them in a weeks time, rather than two weeks time. And…I guess I guess that’s the special care we give for these children. And actually em those the especially the preterms em they I think they have a different clothing uh huh to keep them more warmer uh huh. Those who can’t regulate their temperatures even though they are not fit for the incubator anymore we bring them out and we have special clothings for them. And then we wrap them really well, put them under light so yeah so I think that’s also special, yeah.

I: Ok. Are mothers typically given special instructions for caring for babies that lived when you thought they were going to die?

P: Um is that in the hospital or when we discharge them?

I: Either.

P: Either. Well I think em in the hospital every every instruction is written in the folder and em one thing I realize about NICU department is that em they work they really work well as team together. So em whatever you write is what they will do. Em we know I think we have our specialist coming in regularly to make sure that everything is on point. So I don’t think I don’t think that ehm and one thing that we are always encouraged to write even if it’s even if you think that it’s trivial, you need to write in the folder because when you go to court everything is proven by what you’ve written. So I think that we write almost all our instructions down if not all. We write almost all of our instructions down and every instruction is vital. We have our consultants coming in regularly, em we have our principal nursing officers here and senior nursing officers here who also go through the folders all the time. So I think post em when the babies are discharged, that is post-admission, that’s where the challenge is. Uh we have a lot of these mothers who are uneducated they go back to a lot of traditional beliefs irrespective of what you tell them. And some of them just don’t come back to the hospital so you don’t know what happens next uh huh. Em yeah so I think those are the main challenges there.

I: Mhmm so do you feel like usually mothers understand the instructions that their given, well on discharge?

P: Well em I think some do especially the educated ones. Eh I always say that em our local languages em don’t give provisions to for certain medical terms. So even trying to translate as a doctor who em is fluent in the local language from English to, let’s say, Twi or Fante, it’s a little bit quite challenging. And if you don’t speak the language of the people you don’t get them to do what you want them to do and that’s where the challenge is. So you might happily explain your kidney failure, your heart failure, your sepsis, your kernicterus, your kernicterus and everything to the mother but you don’t have these things in our local language. So it’s maybe the mother may not be able to totally understand what you are trying to put across but she will just agree with you uh huh. She will just agree.

I: Uh huh. So like in cases where you find out mother has not followed the instructions, what is usually the reason why?

P: Um so the reason why maybe communication, the first thing communication, first thing. And um two cultural practices so when they go home, their mothers, their grandmothers tell them so many things that, ‘No em this is how this what it actually is, don’t mind the doctors, they don’t know what they are doing blah blah blah.’ And so they also have to listen to their mothers and they are the one that stay with them at home. So they listen to their parents. So it’s communication on our part em maybe due to the language barrier and then em social pressures from the house to also work yeah.

I: Mhmm, so besides um of the people the have in the home are there any other cultural barriers you believe exist to them following instructions?

P: Em well you can have something like em taboos. Yeah taboos, em I’m not picking, I’m not getting one off the top of my head but em there are certain taboos em em yes. So let’s say em you have a child they tell you that em the child when a child is born within the first em two weeks the child is not suppose to go out. Then you have and then you take a history, you realize that this child has been indoors for the past seven, eight days comes with, to you with jaundice. And then uh maybe everybody’s different but maybe the jaundice is so bad it’s now causing kernicterus. And that is a cultural a taboo, do you get it? So when you get home they are actually scared to bring the child out and all those things and that’s how it affects the child.

I: Mhmm.

P: So that’s an example.

I: Ok. Alright so have you ever discussed ones of these cases of babies that survive when you thought they would’ve died with your supervisor or a co-worker?

P: Um, well we discuss cases everyday. Em we treat every baby em in a in, let’s say, with priority yeah. But em priorities are also relative, yes. So the ones that we think need more attention are given more attention and because of that we have a separate room for them. And those who need less attention are put in a different category. The babies who need more attention are seen first and you always discuss those cases with uh seniors uh huh. So we discuss cases everyday.

I: Mhmm.

P: Yeah.

I: Ok. So like when the cases of babies that almost died but make it come up like what is usually the outcome of those discussions?

P: Well, I think at the end of the day em as I say, we don’t have the proper monitoring tools so you can’t conclude which which of your managements em helped. But we do the best that we can and if if a child survives, we are all happy at the turn of events because benefits are slow. We don’t have very proper documentation about these near-misses ourselves so at the end of the day the child is out of the woods and we just manage the child until the child is fit to go home. That’s what we normally do.

I: Ok. Um…have you ever received formal training on how to handle these cases of babies that survive when they look like they were probably going to die?

P: Well em housmanship training is em a period, it’s a training period as well uh huh. So em everything that you do, you do under your supervisor. Em we discuss our cases every day and em it’s assumed that supervisors have more experience and more technique so as of when it’s applicable or as of when it’s necessary em they teach us the necessary skills. So I think that I don’t have all the skills but eh during um I’ve been learning a lot from them yeah.

I: Do you think there needs to be more training on how to handle these kinds of cases?

P: Well em I think that problem comes from our health system. Em you you have a situation where em as a house officer, I just have six months in pediatrics so after two months and two months in NICU so after that two months I might never come back to NICU again. You have medical officers who are shifted around all the time and we don’t really have a eh we have one neonatologist but he’s also overwhelmed with actually the pediatric department as well. So he’s like doubling up. So we don’t have, let say, um a dedicated em team em to the NICU. The doctors are coming in and out probably each and every day. And you train them and then they take their knowledge away and then maybe they end up, let’s say, pathology.

I: Mhmm.

P: That one, (laughs) you get it yes, that’s [inaudible-18:23]. So eh yes, (phone rings) we need more training em but it would it would’ve been better if em, let’s say, you know that this person wants to do neonatology. So that person is dedicated to the em NICU. And somebody like that would be invaluable actually yeah.

I: So in the case of giving more training to someone that’s know they want to do neonatalogy, what kind of training, extra training do you feel like they would need?

P: Um so em in Ghana you em you need to you need to specialize. It needs to be pediatrics before you start specializing in neonatologist. Em we actually em we you can do your medical em, let’s say, you complete as a medical officer you can stay in the NICU and then if you have somebody like that. Em we have a specialist, specialist would be imparting knowledge onto the person until the person goes to school. Em what happens also is that if you have somebody like that if there’s any em conference or if there is any training program going on, that person is the first person who is going to be mentioned or the first person who is going to be called at this em in neo neo in neonatal training somewhere. So since you are the one dedicated to this place you go for it yeah. Um I think it’s all about getting one one person or two people who are dedicated to it and it makes the training much more easier. Um there may actually be programs outside that the person can apply for, the hospital can apply for the person to go for and all that things. But since we don’t have a dedicated person it makes it difficult to start start those kind of stuff yeah.

I: So just in general, what do you believe is the most important thing to understand in order handle these cases of babies that survive when they look like they were going to die?

P: Um I think that well em your history is always important, you always need to get a history. You need you need to pick up examination findings and your investigations. It’s based on your it’s based on these three things that you make your clinical decisions. And when you make your clinical decisions the availability of the logistics to implement your your plan em most of the time you know what to do but you can’t you can’t do those actually. Excuse me, NICU is calling me sorry (looks at phone). You know what to do but you cant actually do anything about it because you don’t have the logistics to implement the policies [answers phone, taped paused, then resume]. The question again, sorry.

I: Oh, uh you were saying the overall things to understand, so you were saying like they need to know the findings and the logistics need to be in place for implementation.

P: Yeah, yeah so I think em based on that em since we don’t have the logistics, since we don’t have the em the ability to run the labs it kind of makes it very difficult em to actually come up with a formative plan. So let’s say a child em a child being seen in in our facility would have let’s say uh 70-30 (phone rings) percent chance of survival but if that same child was seen in the US or in the UK where the health system is up to date the child might have a 90-10 percent chance of survival. So I think em maybe uh our infrastructure and our lab investigations are main things that end up. Because it’s not as if you don’t know what to do but it’s just you don’t have the ability to carry out the plan, yeah. So that’s it.

I: So considering like those barriers are in place, what would you say is like important thing to understand in order to like successfully handle cases?

P: The question again?

I: I said so since you know those barriers exist

P: Yeah.

I: what do you think is important for health care workers to understand in order to successfully handle the cases?

P: Well um…it’s I I kind of get your question right. But from the onset the the well-go [/get-go/] your hands are tied

I: Mhmm

P: Uh huh from the well-go [/get-go/] your hands are tied. So you you try and do your best. So if the child ‘cause in terms of our fluid management, um all our childs eh all our children um get em a perfusor uh huh, especially the preterms. Em the the children who are little bit heavier who need a little bit more fluid we have a [inaudible-23:17] that regulates the amount of fluid. In terms of antibiotics em we we do well with that. In terms of if a child comes with sepsis, em cord bleeding, em, let’s see, em jaundice all those things. We are able to deal with them but when theres a little bit to be done: a child has a congenital heart disease we can’t do any echo an echo in our hospital em so you don’t you don’t know whether the child is going to you don’t from what I’m saying, you don’t know whether it’s going to be a cyanotic or acyanotic heart disease. You can’t you can’t make any meaningful em decision on what to do and you don’t even know whether it is patent foramen ovale and if we give NSAIDS it will just close it. So these are these are the challenges that we face. So you know what to do but um we don’t have the logistics to help you do what you have to do. And that’s where the limitations the limitation comes comes in.

I: Ok. What do you believe is the most important thing that mothers need to understand when your discharging their baby?

P: Umm mothers…

I: That almost died.

P: Yeah, I think mothers need to understand what their children had. Do you get it? You need to let them know whether it was because em it’s genetic or whether it happened at birth or whether it was post em post em during the post natal period. Em the contributing factors to what caused em the child be in that situation. And I think em mothers also need to trust doctors actually. And trust doctors more and then listen to the people in the house less. Because you tell them one thing and then they go home, their grandmothers, their mothers tell them that, ‘No this is not it.’ And then they take it like that. And maybe sometimes a recall of maybe em you giving them certain instructions or you’ve spoken to them then you tell them to tell you what you said back and see whether they understand it. And I think maybe the use of diagrams may be very beneficial as well. So you have pictures and showing them basically this and that, this and that, and why this why that uh huh. Em try as much as possible to not be too scientific in the explanations; em come down to their level. It might be difficult but em we have to we have to try. And em sometimes too we need to let the mothers be part of the management.

I: Mhmm.

P: Let the mothers see the baby em everyday em inform the mothers about what you want to inform the mother about the child’s condition everyday. And I think when the mothers are part of the management em it it it it brings about a bond that you can’t really explain. Um most of the times uh we just come and see the children and then we go. And the mother just comes, comes, has a look at the child, and also goes, nobody tells them anything. So I think mothers too need to be part of the management of the children.

I: Mhmm.

P: Yeah.

I: So you said like um like important thing for them to know is like what happened with you know the background. Do you feel like mothers are usually told those things?

P: Em I think mothers are told em some of the times. But how em how you’re going to ex—if you just tell the person that your child has kernicterus how does the mother understand it. The mother doesn’t know what even causes kernicterus she might have never heard of it in her life before. So it’s not even something that is readily going to register in her mind in the first place. So em yeah I guess some mothers know, some they are told and they forget and then they will come and say they don’t know. Some too don’t know especially those who em let’s say they were taken for cesarean section uh huh. Em they don’t get a chance to come and see their babies, maybe they are ill themselves so they can’t leave the obstetric ward obstetric ward uh huh. So you don’t they don’t get the chance to come and see or hear what is going on with their child too as well, yeah.

I: Ok. Are you familiar with the term near miss?

P: Well um well I came here and I heard about it. Yeah but um I’ve had I’ve read a little about it. Maybe I know a little but not a lot.

I: Well can you tell me what you think it is?

P: Um well I was, I had the impression that em if you have a child or a neonate uh huh, you are managing the neonate and you expect either you expect the neonate to die or you have a neonate who was doing handling very well and then all of a sudden em goes down. And then after a few couple of things in terms of your management, the child comes back up. So I was think it was related to that.

I: Mhmm, so yes. I mean I would I would agree that that’s what a near miss is. A baby that looks like they were gonna die but they, for whatever reason, make it. Um do you think all healthcare workers all have the same idea of what a near miss is?

P: Well…mmhmm…I won’t think so.

I: Mhmm.

P: I won’t think so.

I: Why would you say that?

P: Why would I say that, because here our system is kind of structured in a way that uh the doctor writes something people don’t normally question. So it’s just like doctor has written this, le’ts follow, doctor has written this, let’s follow. So until the doctor brings it up nobody really bothers about it yeah. So I I don’t want to put it on the same scale. I think that doctors will be more inclined to knowing what near misses are than um than um the nurses and the auxiliary em staff as well.

I: Mhmm, do you think like the distinction of a near miss like saying a baby is near miss versus not is useful to you as a healthcare worker?

P: I think I think em its very helpful. Em it’s allows you to assess what was going wrong and then what you did that changed the situation. And it can be used to implement policies actually, especially em in terms of procurement or something like that. So you have one child maybe with this serial arterial blood gases for the child, you realize the child is acidotic, and through that through the serial blood eh arterial blood gases we were able to manage the child, the child is now fine. And we get a couple of those you can push for a policy to be made in terms of procurement, in terms of national health insurance, in terms of em hospital policies as well. So I think it’s really important.

I: Ok, um so so you would say if you knew a baby was classified as having a near miss you think that would change how you managed that baby?

P: Um I don’t think I don’t think it will change my management because I would do I would treat the baby accordingly according to what baby has. So if I know the child has thermal, let’s say, em it’s a preterm and it’s having eh we are having trouble with the incubator and the child is not able to regulate their temperature. I would do my best to em make sure that the child is warm. I would not say just because the incubator is not working theres nothing I can do. So em in all cases I would manage the cases to the best of my ability. So eh if if you say that they need special treatment, eh I think it means that em you kind of ah eh prioritize babies differently. But I think all babies need the same em label em priority in terms of their management so you do what you have to do. And then if you can do more, yes you do more but your more is based on your lab investigations and equipments and your nursing staff and all those things.

I: Mhmm, ok. What challenges do you think babies who experienced a near miss will face as they age?

P: Em, I think the main thing would be em developmental delays especially in children who, let’s say, em severe asphyxiated babies em who normally em need a respirator just to em let them like let the respirator do the work and the body heal itself. Em I think developmental delays are the things that em you pick up and I think it’s actually em the only reasonable measure that you can use to determine whether a child is growing well or actually not growing well. And then based on that em you can order the necessary lab work for investigations to support your hypothesis, yeah.

I: And so so do you feel like the healthcare system is prepared to do those things to address whatever challenges they have?

P: Em as of now no, as of now no. Em you you you have you have the simple things. Let’s say you can check the baby’s weight you can check the baby’s height em plot them on the centile charts and all that to assess growth. But then when it comes to cognitive em part, you have a child who is not walking, em you have a child who is not talking, you have a child who cannot hear. Em we don’t have speech therapy, we the ?(endometries)? are so expensive em they are done in selected places and most of our people are living on minimal wage anyway. And this it’s these things are not covered by insurance too as well. So I don’t think eh our system is prepared to help these children as they grow along. And our social support system is not the best, another thing. Both in the house and social welfare. It’s just not the best.

I: Ok, so what do you feel like is needed to so you know we talked about near miss being like a baby that looked like they were gonna die and they make it. What do you feel like is needed to increase the number of babies that make it, even though they looked like they were about to die?

P: Em so as I keep saying infrastructure, em em more nurses, em so that our nurses to babies ratio decreases. Em laboratory investigations to support and then to help us in our treatment management. Em policies, having em some of these conditions and some of these investigations put on health insurance so that then the mothers don’t have to have all the burden. Strengthen our social support system. Strengthen em our monitoring system. Give more personnel em, those people who are interested in subspecializing, especially in speech therapy, cognitive behavioral therapy and all those things. Those things are really lacking here. Occupational therapy for our children who have CP [/cleft palate/] em and all those things so yeah.

I: Ok. Um so you know a baby can have a near miss and then they go on to live what do you what do you believe is needed to make sure these babies live long term?

P: Um I think monitoring is a most important thing. Em as I said earlier on our society is difficult to monitor patients, sometimes they go home and they don’t come back again. Sometimes they go and then come and they don’t miss the person who took care of them at first so the person just rushes over, sees the general well-being, but doesn’t delve deep into what was actually wrong and then how far far the child is. Maybe the person might even meet a pediatrician when the person comes back to the hospital uh huh for that third eye. So I think these are some of the problems they are facing.

I: So do you know of any cases of like babies that had a near miss that died later? And like what is usually the reason why that happens?

P: Um…hmm…As of now I would say no.

i: Ok.

P: Because when you are in the NICU you don’t know what happens at the OPD, you don’t know what happens at the emergency. So em maybe we had a near miss we discharged home, the baby came back to the emergency and it doesn’t get back to me so I really can’t stick out my neck to say anything about that.

I: Ok. Do you have any other comments about near miss, um how their treated, or anything you think is important for us that are doing the research should understand?

P: Um I I think that you… you first need to take into consideration the level the level of expertise we have here. Em compared to em other other countries yeah. I think here em the whole Central Central Region I think we have like just three or four pediatricians.

I: Oh.

P: And I think three of them are here. Do you get it? Uh huh so we don’t have the necessary em people em to em to help in our diagnosing and other development and all those things. So they could be a lot of other near misses going on in other parts where they take care of em em neonatal cases and all those things. Em also you need consider the I believe the gap in technology as well uh huh. In terms of em laboratory investigations, radiological investigations and all those things. Em we just we are we just don’t have the technology to do em complex em laboratory investigations. Even if even a child needs surgery, we don’t have a resident em neonatal surgeon. We don’t even have a resident pediatric surgeon, how much more a neonatal surgeon. So if a child needs, if a neonate needs to be taken to theater, we don’t have an intensivist, we don’t have eh we don’t have a resident anesthesiologist going to doc off a neonatologist uh huh. So em mostly personnel, infrastructure difference, it’s it’s main it’s the main thing. But the knowledge there its just we don’t have the things to work with to implement these things, I think that’s the main problem, yeah.

I: Ok, well again thank you for your time for answering our questions. Uh we hope your answers will help us understand more about why babies that seemed as though they were gonna die live instead. Please let me know if you have any questions.

P: Uhh I really don’t.

I: Ok, well if you have any questions in the future I can be reached through \_\_\_\_\_ who you met.

P: Yeah.

I: Here um so you can also ask her questions too.

P: Yeah.

I: And…

END OF INTERVIEW

Type: HCP Interview-KA9010

Date: 02-07-2015

Position: Nurse

I: Uh thank you for taking the time out of your schedule to meet with me today. Uh as I’m sure you’ve been told, this project is focused on learning more about the babies who have life threatening complications during and after delivery, but who survive. Your thoughts and opinions about why some babies survive while others die are very important to helping us understand these issues better. As a reminder, I will be recording the interview. This is just so that I have something to help me remember what we talk about. It also means that I won’t take as many notes. Just whatever I want to follow-up on. Just so you know, these recordings will never be played publicly. We will transcribe them and then destroy the tapes. If there is anything you don’t want to talk about, please let me know. Also, we can stop the interview at any time. Please let me know if you would like to stop. We would like you. Er what we talk about will remain confidential. I won’t share the details with patients or others at the hospital. You will not be named in anything that is written about the research. And just so the tape knows, this is interview KA9010. We would like to learn more about your experiences with babies who are ill and their outcomes. You’ve been working on the NICU for \_\_\_ years now. Uh, some of the babies have severe complications. Some of them, you may have struggled with and they died. Some of them, you may have struggled with and they lived. Some died no matter what you did. Some lived even though they looked like they were going to die. What do you think was the difference between those who lived and those who died?

P: Those who lived, I would say, as a result of prompt intervention. Yeah, because most of the time when they come and it’s um the there’s a terminal age or a terminal stage. No matter what you do, some of them will die. But those most of them, those who live, when they come, it’s for an intervention. Like currently, most of our drugs are uninsured. And when they come and we ask them to buy this drug or that. Those who have access, like those who have the money, they can buy them. And they use it. But those who don’t have, though, they they can’t buy it. Once the drugs are not there, there’s nothing you can do about it. So I think eh it’s prompt intervention. Like those who actually in the complicated stages like those who come then they’re able to do something to survive, it depends on; I think it’s yeah prompt intervention. How they get access to the drugs and yeah. Because most of the drugs that are current, the original ones are uninsured. You have to buy them before you use it for them, yeah. Drugs like adrenaline is not insured. Yeah, phenobarb is not insured. You know emergencies, somebody is convulsing and you are supposed to give you something and the drug is not around. You have to buy it. Takes time. You don’t survive.

I: What do you think can be done to like speed up the process, if anything?

P: Hmm. I think erm, it should have. I think we need to have an emergency drug box there. But the problem is that when some, when you use it, occasionally it becomes a problem. So when you go to the pharmacy for them, they won’t even give you again. So I think what’s, so you thought we can do it that maybe I don’t know from our own cupboard or whatever and you get some of the drugs that you think are. Like the expensive ones or the really ones that they are good that we can use them and the emergency ones like the adrenaline, phenobarb and those ones we use immediately. If you have them in stock, so that when they come you use it for them. Later on, you find the way of replacing it. I think, to me, that’s what I think can be done like those ones yeah.

I: Ok. Can you tell me more about your experiences with those babies who lived when you thought that they were going to die? Which condi—conditions or diseases did these babies have?

P: Ehm as for that there’s one, there’s one that’s at hand. I would find there was a time a baby came, it was a preterm baby. It came with a with intersepsis—sepsi—sepsis. It had episodes of apneic attacks. It got it got to a point that em the mother even gave up. She said like, she want to go, whatever happens. But the baby for about five minutes apneic. Baby in apneic state you have to bag and all that. But surprisingly, that baby survived. In fact, we all lost hope. But I don’t know what happened. That baby survived. Though that baby. That baby too, the mother was financially sound. I mean, whatever we, I think we changed to about the second line antibiotics or something. Whatever we asked the mother was able to buy it but it was episodes of apnea and but the baby survived. The baby survived. Had hypothermias and he was always under the radiator but I don’t know what happened but that baby survived. And it it’s one case that I actually felt like because of that baby now that even if a case is bad, you don’t have to ignore or just give the false hope like that. Because of that one. So I think sometimes when they come and then they go the state, (sucks teeth) poor state or whatever you should try as much as possible to do something because you don’t know, you can’t even predict what will happen to them.

I: Uh another question about. So the parents that can afford the medication, does it still take a long time to, like is it actually a longer process still to get the medicine? Like it’s almost like you have to go out and buy it and bring it back? Or is it like, oh I can afford it and so y’all have it and can give it?

P: No. It it it depends. Um some antibiotics like, we have our first, second, and third line. Like the second line drugs, they’re usually expensive than the second and third. Like claforan and those ones you you don’t have them here. It’s not even in the hospital. The local pharmacy doesn’t have it so they buy it from private pharmacy. But it’s just around, uh huh. But the emergency ones like the like the phenobarbs and the adrenalines, it’s in the pharmacy. So somewhat what we do is that (laughs) well it you know when they come and the babies are in poor state. When you ask them to bring the money or they will bring it. So we let somebody go up and bring it, like, and buy it. But most of the time, there are other babies who are around, like, they have it. Though they are not using it at that time. So when they ask them to go and buy, and then we use what we have. The one that belongs to another patient, we use it for them. So when you come this is the other one’s. Mostly the phenobarb that’s the thing we do. Sometimes, if you let them know that the drug is here, when you ask them to buy they will feel reluctant. They don’t really want to buy it. Because I have a personal experience about that. There was a woman. There was some bottle, I had phenobarb, I think it was from the emergency one, by that time we had. So I used it, so I waited for the mother to go and buy and I could replace it.

I: Mhmm

P: But that woman wouldn’t buy the drug. And so now for that one I had to use my own money for that one. Mhmm so sometimes, though we have it, we want to use it for them, we don’t want them to see that we are using it so we just try to keep it behind them. I know that. As for the antibiotics, we have to buy, we have to go to the private pharmacy and buy it. But for the emergency ones, you have a way of getting them some, yeah. And basically (mumbles off). But for antibiotics, there’s nothing you can do. You have to buy them for each time. Mostly, when they are put on the, erm. As for the first line, it’s available at the pharmacy there the generics ones are there. But even uh the first line, even if you still want them to use the original one, they have to buy it from the pharmacy. So eh, as for those ones, if you don’t buy, you don’t start. “No, I don’t want this to have it.” But you don’t want to start it, well you’ve not bought it. Because with the guarantee that when you start it, you buy it for us to replace it and we can’t continue. Heeh so those ones before we start, we make sure that it’s there, then we start. We don’t want to start and then stop and then (mumbles off).

I: Ok,umm is any special care given to these babies that lived when you thought that they were going to die once their condition has resolved?

P: No, not not any special care. I think once they survive, then they’re okay. We just they do the when they are discharged we do the normal the the normal follow-ups. But for the preterms we have special care for them. We have everything that they come for, weighing, if there is any change, they are not like the term babies who survive and then okay. But for the preterms, whether it’s umm they survived and then or if it’s… No matter what after the preterms they come whatever they need for. Say there’s anything you can detect it but the normal ones like the term babies, you don’t have any special care. Unless maybe they survived but with a complication, like em jaundice with kernicterus and uh but in discharge they have this we refer them to Physio for eh exercise. But for those who don’t have any complications after they survive we don’t we just a normal, those with complications we refer them to the appropriate place.

I: Ok, uh are mothers typically given special instructions for caring for babies that lived but you though were going to die?

P: Yes, yes. Most of them em about their feeding. We make a lot of efforts on their feeding because of maybe aspiration and those things uh huh we give them special education before they go. And most those babies we we even give out our numbers just in case they are doing something and you notice any change in the babies like their temperature, their feeding part or whatever. We give them our numbers to call, uh huh. So maybe then even if you are not around and they call and there’s a problem we ask them to come but we put somebody around to tell them that this baby is coming. As for those ones, for the numbers, we give it out. Because you don’t know, so we give our numbers out. So if there’s a problem, you call then we lead them to the people on duty. Cause when they come and the persons on duty doesn’t know the person they will ask them to go through poly or lay like a long process. Or once you call them to explain to them “oh this baby was here so that oh maybe she’s coming back.” Get them seen or something, uh huh. It will be done. (laughs) even if we don’t give out anything like that, they come straight. Have to go through the normal OPD unit [crosstalk] and the stress.

I: Do you feel like the mothers usually understand the instructions?

P: Umm not all of them but most of them when I’m giving instructions to somebody, it depends on how well the person will relate with you or maybe the questions the person will ask. Most of them when you are telling them something they just look at you and everything you get note and you see that. But those like those who you tell them something and they do also ask back. Maybe tell them, “Oh if you this they you child is cyanosed oh madam what is it.” We explain that or if maybe their hands are blue or whatever like the science they’ll say oh ok… So they even ask back. So if this I should do this. Like those ones those who interact we know that they are really understand but those who don’t say anything we just know. We see that. We have to stress for that you even ask them back. You do it, so what did I say, then uh huh. So we do that. So you know that it’s gone on well.

I: Ok, so when mothers don’t follow the instructions what is usually the reason why?

P: Mostly it's it's it's hmm, I would say most of the maybe it’s it's financial or I would say home support. Well most of the time, ehm when they come here it’s really stress for them, stressful. Even where they sleep and all those things. So even when you are telling them to maybe if there’s a problem come back or whatever, they even have in the back of their minds that I’m only here for here after here I won’t come again. Even though you are telling them the person is not going to return. But you have that at the back of their mind that when you are here I won’t come here again so I think that’s what either stress that they go through when they come here, where they sleep it’s a problem. Most of them their cot here, they are sleeping on the bench and it’s very stressful. So they will decide not to come back. Most of them too most of those who even um those with those babies not em. Such babies most of the time because they stay here for longer than one month, six weeks and all that. And it's stressful because of like the time we spend here going home telling them to come back they will compare the two. That should I, it isn’t it isn’t worth it, thought the baby survived. But is it worth it eh like considering how the patients suffered like even the mothers have suffered when she was around feeding and all other things. I think those who don’t even pay attention it’s because we can tell they won’t come back so they won’t even pay attention to you. That’s what I think.

I: Do you feel like um oh well what cultural barriers exist between mothers following the instructions?

P: Cultural…as for cultural barriers…hmm it’s not a only I don’t know whether it’s a cultural or religious. Like eh we have some Jehovah’s witness like uh some if somebody comes with anemia or maybe a severe jaundice that you want to do an exchange transfusion or you want to transfuse. And because of the way they are, their religion, they will refuse, they don’t want to do it and that. So with such a mother, ok maybe em some may happen then the baby is transfused though against the mother’s will and such a mother, if the mother is going home and you you tell her when you go and you see the baby is pale or whatever, bring the baby back. Such a mother will not come back. When in the first place what you did was against her their belief, their religious belief. It’s not (mumbles) such a mother will not come back.

I: Mhmm

P: Yeah, so with that one, it’s only that one that I can say that it’s the only religious belief I think is a hindrance besides that culturally we have not had any problem like that at our end.

I: Ok, have you ever discussed on of these cases of babies who survive when you thought they would’ve died with your supervisor or a coworker?

P: Yes, oh that’s the baby that I talked about. The preterm baby and aspiration and…it was yeah. That baby I actually discussed with my in charge, my boss and even it was our subordinates. So we are all like, the issue was ah this baby like (laughs) whenever somebody come and say ah what is this baby, he like he’s still alive and then they all surprised. So when the baby was discharged everybody was surprised. Cause this baby who had series of apneic attacks and bagging bagging bagging and baby wasn’t going to survive. It was something that within us we were all surprised. So we we discussed among ourselves that if something you bag and you be tempted to stop, so we decided because of that baby, if a baby comes and it’s suppose to bag maybe had series of apneic attacks and was suppose to bag baby if you considering bagging till maybe the heart is no more.

I: So usually when you discuss cases like this what is the outcome of the discussion? Would you say it’s like what you said new ways?

P: New ways, even em…eh the ways you go about our um how we do the maybe our care. Our care, I think sometimes when cases like that happens and we start we discuss them. We actually discuss that we should…like we should modify the way we do our how we do our resuscitation and all that. Most some of them the way we bag, maybe the technique is not there. How like like we should modify the way we do our, this thing like we have we take care of our emergencies. And bagging, like the skills, bagging and whether it’s just compression or whether we should know how to do it for.

I: Ok, have you ever received formal training on how to handle cases of babies that survived when you though they would’ve died?

P: No.

I: No. Do you [crosstalk] Do you feel like there should be training?

P: Yes, I do (furniture in room moving) I think so. Because if eh there are things we think they are hopeless but later on I think there should be trainings like that. I think that it will help a lot.

I: Mhmm

P: It will help. (furniture moving) So that we don’t we don’t give up on cases.

I: Mhmm, so what kind of training do you think would be useful?

P: Mmm, lets what’s asking the method of training or how like like…?

I: Like what should you learn, what should people learn in the training?

P: Mm, I think it should be both on um maybe eh I don’t know. Like the emergency like immediate maybe like resuscitation. And then even em their follow-ups, yeah their follow-ups. Because most of the time when they are discharged from me that is the end. It’s only a few of them that. I think there should be em eh there should be a training on how those babies are given special how how they are given special care. I think they should give a formal training on something like that.

I: Mhmm

P: Well once they are discharged you don’t see them again. That’s the end, yeah.

I: What do you believe is the most important thing to understand in order to handle these cases?

P: Most important thing, mmm…um hmm. I think what em most of the cases we should you should know um like most of the hmm I don’t know how to go about this. Like you bring up the question again, I don’t know how to. You bring about the question [crosstalk].

I: Oh you want me to say the question again, ok. What do you believe is the most important thing to understand in order to handle these kinds of cases?

P: Like those which like with those who were like emergencies and they [crosstalk]

I: yeah, the babies that survived when you thought they would not have. What do you think is the most important thing to understand about them?

P: (pause) For those ones, I think hmm. I think it’s still part of the same thing that we shouldn’t. Oh we shouldn’t be like say such cases…hmm…(furniture moving) I think (laughs) most of such cases we should eh I don’t know. We shouldn’t I don’t know how to go about that, we shouldn’t ignore them, yeah. We shouldn’t ignore them, even like when such cases come. I mean after maybe after an experience about the case. Once such cases come again I think we should we should we should have positive thoughts or something about such cases yeah.

I: Mhmm

P: We can’t just ignore because of because of the experience we have had. When such cases come, I think we should also have positive minds or something so that you can…umm you can help them. (pause) And also um… most most (laughs) of the time when such cases come we have this em em like maybe our morning meeting. We have those eh presentations uh huh. So we discuss with our bosses. And sometimes maybe management-wise they all (stammers) but brings up something. They all come out with their views or something on how to manage such cases. Though manage to do something for the baby to survive. But at least we discuss further so that once such cases come again, we know how to go about it.

(pause)

I: Ok, what do you think is the most important thing for mothers to understand when you’re discharging the baby?

P: Oh when… mostly when they are on admission we discuss not all of them, some of them are practically, they ask a lot of questions. So we explain their condition to them and all other things. So when they are discharged we tell them that eh like as we discussed with the baby (horn honks in background) as we discuss the baby’s condition with them we should um like when they are discharged we tell them about their follow-up. The day they will come for visiting order. We will also tell them that when they see any like any of the danger signs, like maybe the child is worse, the child is not feeding or if there’s any change in the baby’s attitude. We should wait till the review date or the follow-up, they should just inform us, yeah. But those with special cases like those that we thought were dying and they survive, as for those one, as I said, we give out our numbers to them. If there’s something, they call before they even come. In the normal cases we don’t give out our numbers we just tell them the follow-up meeting and everything. But then we tell them if there’s a problem, they shouldn’t wait till their review date they should come.

I: Mhmm

P: We tell them quick reports. We don’t allow them to come here straight; they go to through the OPD. If it’s uh night or weekend or something they go through the normal OPD. And if there is a need for them to come up, they will come (sirens in background). So that’s what we do.

I: Ok.

P: But most of them we are really invested in their feeding. The exclusive breast feeding we learn but those who don’t, most of them they don’t even do the exclusive they will come here already giving the um bottle feeding. So those ones we have to tell them how to do the preparation, the hygienic aspect. So that they won’t come up in (mumbles).

I: Are you familiar with the term near miss?

P: No.

I: Ok, uh a near miss is kinda what we’ve been talking about. When a baby looks like it’s not gonna make it but it survives somehow, so you know you nearly missed them. You can also have a maternal near miss, neonatal near miss. But we are talking about neonatal near miss in this case. Um do you think having that distinction of a baby that had a near miss is useful for healthcare workers?

P: Umm the near miss, the baby that you though was going to…

I: Thought was not going to make it but they do.

P: But they do, ok. So you are asking, ask the question again.

I: Do you think having that distinction is useful as a healthcare worker?

P: Yes. I think it very useful because it it kind of differentiates the the the…like the babies who are on admission. Because there are some that are just normal cases but those the near miss it’s means that like there’s something that we did that if it had not been done, the baby would’ve we’d have lose that baby. So that baby needs an extra care. Yeah that baby actually needs an extra care. If you don’t take care this near miss you easily miss the baby. So once you don’t think they’re surviving I think the case should be, it should be sort of (stammers) I don’t know whether it’s strict care or something. We should keep an eye extra on such a baby. I think that distinction, it should be there because if it’s there you will be able to, you know how to manage, you know how to care for those babies. And that’s a way if that you differentiate among them but there is some special care that you can give out to do with such babies.

I: Ok, so so if you knew a baby was classified as having a near miss, do you think it would change how you managed that baby?

P: Mmm, it would change it. Yes yeah it would change it. Because most of the time if it’s um like maybe if that baby’s you have to monitor that the baby’s [inaudible-25:53] or something and you are short of, um ?(repositories)? You have a way of keeping something, most of the instruments that are that we don’t have available. We have a way of keeping some for such a baby but you know that in the slightest thing, you can miss that baby. So you have, you give an extra care. That distinction should be there its it will help.

I: What challenges do you think that babies who experience a near miss will face as they age?

P: Um, I think um most of them can have…um. I think the level of intelligence can be this I think it can it can maybe their IQ yeah I think it can be a bit slower.

I: Mhmm, you said the level of what?

P: Intelligence.

I: Oh how…?

P: Mhmm cognitive or something.

I: Mhmm.

P: And then because like the babies that you bag and bag and bag. You are suppose to do it then you will have all of the brain there. And sometimes maybe their speech you know not all of them, they are near miss but not all of them are not fully sound as in like those with kernicterus that who were able to survive, most of them they come up with eh secretly like most of them they have ear problems, sometimes their speech. They have some you know I wouldn’t say all of them, some of them will have deformities, yeah.

I: Mhmm, and how do you think the healthcare system will respond to their needs? As they get older, if they have those kinds of needs?

P: Um I think eh ask that question again. You said how the hospital will…?

I: The healthcare system will respond to the needs of babies that experience near miss as they get older (phone ringing in background).

P: Mmm, there is suppose to be [inaudible-28:01] for discharge. I think it’s eh they can help. In this current situation like if all things were equal, everything is in it’s place. I think the hospital can do a lot to help them. Like those with maybe um like I said if it’s something to do with their movement or something they can go to physio. If it’s ear or eye problem you can go to the various department, those that handle those cases, yeah. But we don’t have like certain a complete setting that takes care of them. But it's it’s individual department that you refer them uh huh. We don’t have any special unit that takes care of such conditions but it’s um interdepartamental something. So they go we we refer them they go to the various eh depending on their need, if it eye they go to the eye clinic. If it’s the ear, ENT. But we don’t have any we don’t have anything like that like something that is that can take care of we don’t have anything like that. But so the mothers do that on their own. It’s not like the hospital has something to help. But they do that on their own, like when they come. Most of the time it’s on the follow up that we do those things. When they come, you refer them, if there’s a problem they go to where it is. There isn’t something like a place that will take care of them. Like when they come maybe everything is there they will be seen and it’s… But if you are asking that do I think the hospital can do better to help, I would say yes.

I: Mhmm

P: It should have something like a place, a unit for all of them. So when they come they all go and when they go like that, they meet other children or other their colleagues who have the same problem and then they mix. That one it helps uh if it’s there individual one they do it own and they go and join the queue and go and wait. They don’t even come they just leave the babies. I think there’s a unit like that that will take care of such children. I think it can help. It will encourage their mothers who have those ones to come. That one’s, we don’t have anything like that, currently.

I: Ok, what do you think is needed to increase the number so increase the numbers of babies that looked like (phone ringing).

P: Please let me put it off (referring to ringing phone) (background noise of things shuffling).

I: Ok so what do you need I mean what do you think is needed to help increase the number of babies that live that looked like they were going to die?

P: I think it it’s…um our prompt services, yeah. Our prompt services, yeah. Because when they come and like you ignore them. Like you think it’s a hopeless case so you just leave it, forget about, don’t help them. I think our prompt service will help and then the availability of um logistics

I: Mhmm.

P: And then the drugs, because you are bagging and you don’t have the good ambu bags and those things, it won’t help. So if all those things are in place and the staff strength too are there. And our attitude eh the way we… take care of them. I think prompt service and more immediate immediate management and all that comes into place. Cause we are given prompt attention, it can help.

I: Mhmm, ok. Uh so do you have any other comments about sick babies that are here that end up surviving when they looked like they wouldn’t that you feel like we should know for this research? Just any other comments in general about this topic.

P: Mmm, you bring up the question again.

I: Um so just any other comments like anything that you think we might have not covered in this conversation about babies that look like their gonna die but they survive that you think we should know for the research.

P: Mmm, um I think…umm…no.

I: No, ok. That’s fine. Well thank you again for answering our questions. We hope your answers will help us understand more about why babies that seemed as thought they would’ve died, live instead. Uh please let me know if you have any questions.

P: Mmm um any question (laughs) any question, general question.

I: Yeah if you have any questions for me.

P: Based on what we did?

I: (nods yes)

P: Mmm oh ok. I think I wanted to find out um how the research the whole research is going to help improve the near miss babies (mumbles rest).

I: Mhmm well so it depends on what we find. Um so hopefully if we find something that’s useful. So there’s um people here are that are over the research. We are doing this research at multiple sites so depending on what we find you know that research will be published and then hopefully we gone on to update any protocols. So that’s how were hoping it improves stuff around here. So cause they’re doing more than the interviews that I’m doing. They’re doing other stuff too like collecting data on how many near misses happen and so these interviews help tell us if you know really looking at a near miss is helpful for you in not in helping save a life. So it kind of depends on what we find.

P: Oh ok.

I: Ok so if you have any other questions you can reach me through Dr. \_\_\_\_\_\_.

P: The one that was here.

I: Mhmm. So you can ask her or you can get my contact information from her if you have questions directly for me.

P: Oh ok.

I: Ok.

END OF INTERVIEW

Type: HCP Interview-CC9015

Date: 21/7/15

Position: Medical Officer

I: Alright. Um thank you for taking the time out of your schedule to meet with me today. As you may know, this project is focused on learning more about the babies who have life threatening complications during and after delivery, but who survive. Your thoughts and opinions about why some babies survive while others die are very important (baby cries in background) to helping us understand these issues better. As a reminder, I will be recording the interview. This is just so that I have something to help me remember what we talk about. It also means I won’t need to take a lot of notes, I will just write down what I would like to follow-up on. Just so you know, the recordings will never be played publicly. We will transcribe them and then destroy the tapes. If there is anything you don’t want to talk about, please let me know. Also, we can stop the interview at any time. Please let me know if you would like to stop. What we talk about will remain confidential. I won’t share the details with patients or others at the hospital. You will not be named in anything that is written about this research. Also just so it is noted on the tape, this is interview CC9014, (corrects to) 15. We would like to learn more about your experiences with babies who are ill and their outcomes. You’ve been working on this NICU for about \_\_\_\_\_\_ now. Some of the babies have had severe complications. Some of them, you may have struggled with and they died. Some of them, you may have struggled with and they lived. Some died no matter what you did. Some lived when you thought that they were going to die. What do you think was the difference between those who lived and those who died?

P: Ok. Um I’m not sure what the difference was. I just think it happens. Some people would say [inaudible-1:43]. Cause I don’t think, nothing. I don’t think we do much here to actually help the babies survive. We don’t have a lot of equipment. Even those we have are not functioning and our response to emergencies is actually a bit slow (baby makes noise in background). So I don’t think, eh the babies living or dying has got anything to do with with what we do. I think it’s just by chance. Maybe the babies just, yeah.

I: Mhmm, ok. And so why do you feel as though, well can you speak more to why you feel like there’s not a lot that’s done here to keep them alive besides the equipment and stuff.

P: Besides the equipment, training, most people, I don’t think we know what emergencies are. Sometimes you hear something beeping, you call a nurse, they are sluggish. You say it’s an emergency, someone really doesn’t understand. They are still sluggish. It’s more of training and our promptness to emergencies. We need learn more. You know, what to do, when to do, all we have to do.

I: Ok, can you tell me more about your experiences with those babies who lived when you thought that they were going to die. Which diseases or conditions do these babies have?

P: Um, ok…my experience. A few were severe neonatal asphyxias. Sometimes they come in and they are in very bad shape but (baby in background/cross talk) sometimes you come back, they actually better than they used to be. Sometimes you think they will die, I don’t know because we don’t do anything different from the severe neonatal asphyxias to the mild neonatal. We actually don’t do anything different. Just put them on antibiotics, put them on oxygen. If they are going down, put them on face mask. We actually don’t do anything different. So as to what makes them live, I really don’t know.

I: Mhmm, ok. Umm.

P: Just a minute. And then most of the time, those that we think that will die. Maybe most of them are congential anomalies.

I: Mhmm.

P: Yeah. I think…

I: You said the ones that die?

P: No, the ones that live when you think they’ll die. In my last week, I think we had a patient with oh it was Patau, Patau’s syndrome. And the child actually, initially the child was on oxygen by face mask. We weren’t doing anything. We weren’t really doing much but we thought the child would die because the child had a cleft palate all the way to the back. And someone mistakenly feed with the cup and the child aspirated. So we are prepared for the child would die but the child survived. Or I don’t know usually Patau they don’t survive that long but at least the child was discharged and went home.

I: So, is any special care given after these diseases or conditions are resolved typically?

P: Pardon?

I: Like is special care typically given after like the diseases or conditions that put babies at risk of dying; like you thought they were gonna die, is there special care that’s given afterwards?

P: Um, not really we just try to review them more frequently at the OPD. Seeing their progression, uh huh. No special care other than the preterms that we give supplements, there is no special care to any of them. Most of the time they are having difficulties, we have to refer and sometimes that’s a discharge if we know there’s nothing we can do. We refer them so [inaudible-5:43].

I: Ok, um so are mothers typically given special instructions for caring for babies that lived but you thought were going to die?

P: Um, well special instructions… mmm I’m not sure. If well those with the cleft palate we teach them how to feed.

I: Mhmm.

P: I think it’s a bit, usually the nurses handle that. I think it’s a bit different from how the normal cup feeding is done so that the food (baby in background) it doesn’t [crosstalk]. And then…

I: (whispers) Can you talk louder?

P: Ok (laughs) sorry. Um I don’t think that, there’s really no special yeah. The preterms, they do KMC, I don’t think there’s anything much in special care (mumbles off).

I: Mhmm. So when mothers are given whatever instructions they need to get um for caring for their babies that lived when they looked like they were gonna die, do you feel like mothers typically understand those instructions?

P: I don’t think so. Cause there have been times where they come to the outpatient department with problems that could’ve been avoided. Uh well as to whether they understand or not I cannot really tell because there was a patient um I’m sure what the syndrome was but we taught the mother how to cup feed. And after like a week the child came back, had aspirated cause the mother didn’t feed well. So from that I’m not so sure if they know. Sometimes too the mothers they understand but they don’t want to do they don’t want to do it. There have been a lot of instances they have been taught to do KMC, kangaroo mother care. But they come to the OPD (baby in background) they actually don’t do it. Or they tell they tell the doctor the doctors in the OPD that they were told to do it for just an hour or so.

I: Mhmm (baby in background) And then what?

P: And then they can just carry the baby around instead of carrying the baby all day in that position yeah (baby yelling).

I: Uh so when mothers usually don’t follow the instructions, what would you say is the reason why?

P: Um…uh…(mumbles)

I: Hmm?

P: Sometimes well I will give you an example. Someone comes in, brings a child in, has been uh has been having an upper respiratory tract infection. We don’t give ?(cough medications)? to children, so a child will be coughing. And now you tell the mother do this, do this but the mother comes back and hasn’t resolves. So the mother doesn’t really trust that you know what you are doing. They go home and then they will do what they want to do. And then they come back with complications. It’s not like they don’t understand what you told them but they want quicker results or what you told them they don’t think it will work or it’s working. So sometimes they just choose to do what they want to do. At times it’s illiteracy, then it’s poverty. Sometimes the things you ask them to do it may be neglecting their other children whilst doing what we ask them to do. So they won’t be able to do that.

I: What cultural barriers do you think exist between the mothers following the instructions?

P: I’m not much of a cultural person.

I: Mhmm.

P: I really don’t know (laughs).

I: Ok. Um have you ever discussed one of these cases of babies that survive when you thought they would’ve died with your supervisor or a co-worker?

P: I don’t think so.

I: Mhmm.

P: I really don’t think so.

I: Ok. Um, so (door slams) is it normal for anyone on the team to discuss these kinds of cases?

P: Yeah, we discuss the cases amongst ourselves but it doesn’t go beyond us.

I: Mhmm.

P: Sometimes if you have problems and you inform the specialist about it but I never have asked (mumbles off).

I: Ok. So when the discussions do occur what is usually the outcome of the discussions?

P: We will bring our opinions what basically what what we think. Everyone tells, I mean you can tell what you think should be done or what’s wrong with the baby. And I think I think (mumbles).

I: Ok, um have you ever received formal training on how to handle these cases of babies that survive when you thought they would’ve died?

P: No, I haven’t.

I: Do you think there should be more training on how to handle these cases?

P: Yeah I think there should be.

I: So like what kind of training?

P: Um any refresher course, something how to handle these babies, what we should put them on when they are going, what we should tell their their mothers when they are going home, how they should handle the babies when they go home.

I: How they should what the babies?

P: Handle

I: Oh!

P: the babies when they go home.

I: Ok. What do you believe is the most important thing to understand in order to handle these kinds of cases? Just in general.

P: …Please come again?

I: What do you believe is the most important thing to understand in order to handle these cases of babies that survive when they looked like they were gonna die? Just in general.

P: I think they need to understand what they had in the first place. The condition they had. And then from there you would know what to do if they survived.

[pause]

I: Um, what do you believe is the most important thing for mothers to understand when discharging a baby that almost died?

P: [10 second pause] I’m not sure. [5 second pause] I’m not sure but I think the mothers also need to know they need to know what was wrong with their babies in the first place. They need to understand that one, the baby almost died but for some reason the baby managed to survive um so they need to take good care of the baby.

I: Do you feel like most mothers do understand those things?

P: I don’t think we tell them enough in the first place for them to understand. Some babies come in we actually don’t discuss the conditions with the mothers. Sometimes we just tell them like, ‘Your child is sick.’ You don’t tell them what is actually wrong with their baby (mumbles).

I: And so why why isn’t there more information given to the mothers?

P: I don’t know, in my country um health workers, well most people fear health workers especially the illiterate ones.

I: Especially the what?

P: Illiterate ones.

I: Mhmm.

P: Um they feel like health workers have the power to do anything they want.

I: Mhmm.

P: Yeah. And sometimes they also guess I that they will be mean to the patients. Recently I had one who went to another facility and was managed for something. But (creak in background) when they brought the child here and when I asked him what was wrong with the child or what they told them at the other hospital, they say they don’t know. I asked him why he didn’t ask the doctors and when he asked the doctors they will shout on him so he didn’t feel like asking. So that’s what happens in our society.

I: Ok…um…so earlier when I asked about like the important things for for to understand in general like the babies, when you said the babies’ condition, do you feel like most of the health workers that are dealing with these babies almost die have a good understanding of what the baby had and how they should be treated?

P: Hmmm…well sometimes even the doctors we don’t know what we are handling.

I: Mhmm.

P: But that’s why we are suppose to read in the first place. But the time to read is not really there. So as whether we understand I cant really say. I don’t think we always understand what’s going on with the babies to know what to do. Sometimes we just manage based on the symptoms that the baby has.

I: Mhmm, ok. Are you familiar with the term near miss?

P: (sighs) Um let me ask you for to fresh my mind on that. I heard it, it’s been like a month or two.

I: Mhmm.

P: Yeah. I don’t think I remember the details.

I: Do you remember anything from it?

P: I know it was about asphyxia babies, those who, well what we are talking about. Those who we thought were going to died but survived.

I: Mhmm.

P: Yes but survive actually.

I: Yep, that’s that’s how I would define it. A baby that looked like they were gonna die, we think they’re gonna die but they live for whatever reason. So you like nearly missed them. Do you think um providers all have the same idea of what a near miss is?

P: Um well for those of us here we all’ve been told what at least we all went for that meeting so I think we all know what it means.

I: Ok. Is it a distinction that is useful to you as a healthcare worker?

P: Is it a distinction?

I: Yeah like distinguishing a baby as having a near miss, do you think making that distinction is useful?

P: Well yeah. Oh it will help you manage the patient differently. Well it’s suppose to help you manage the patient differently

I: Mhmm, and how would you manage it differently?

P: How, um…I pay more attention to that baby actually.

I: Mhmm

P: …I think that’s it.

I: Mhmm, ok, so if you knew a baby was classified as having a near miss do you think you would change how you would manage the baby? So yes.

P: Yes it will.

I: And so mainly just paying more attention, is there anything else?

P: Umm, I’m not so sure.

I: Ok. What do you…What challenges do you think babies who experience a near miss will face as they age?

P: As they age…(yells, doors opening, phone ringing in background)… I’m not sure. I’m not sure what [inaudible-17:58] would take place. It depends on the complication they develop yeah. I think it depends on the complication they developed. [door slams] Some of them may have uh delayed developmental milestones.

I: Mhmm.

P: Some of them may have cerebral palsy…

I: Mhmm and do you feel like the health care health care system is prepared to respond to those kinds of complications?

P: Oh please, I don’t think they are.

I: Mhmm, and why not?

P: Well cause we don’t really know…well we don’t really know what the complications are. We don’t have the equipment to manage the complications and our minds are tuned to managing the simple things that come. When it comes to the big things we don’t really know what to do.

I: Ok, what do you feel like is needed to increase the number of babies who survive? Like so were talking about babies you know they looked like they were gonna die but they lived. What do you think is needed to increase more babies surviving instead of dying?

P: Um, at our NICU one, we need immediate response. We need to be responsible for something. And they need to respond faster to emergencies. Some sometimes a baby has hypoglycemia and the baby is just there, ‘give me something [inaudible-19:36],’ you have to try to get everything yourself. We need to actually be fast and know what emergencies are. And then we should (mumbles off).

I: Hmmm?

P: What question am I answering?

I: Uh whats needed in order to increase the number of babies that survive?

P: Mm hardly here, we need at least a CPAP machine which we have. It’s just the installation that’s the problem. And

I: The installation, like it doesn’t work? Or its hard to put babies on it?

P: No the machine is just sitting there in the NICU. They aren’t using it. It hasn’t been connected to an oxygen [crosstalk]. As to why I don’t know. They are trying to get it done anyway but…at least what we’ve done, we have ventilators too you can actually get them some. I think that will help.

I: Mhmm.

P: (mumble) Actually (mumbles off).

I: What do you believe um is needed to make sure babies that have a near miss live long term?

P: Please come again?

I: What do you believe is needed to make sure the babies that have a near miss, once they’re discharged and stuff, like whats needed to make sure that they live long term, like they actually age and grow?

P: They actually age and grow, um frequent reviews. You need to see them more frequently to know how they are going. Then if they come with complications and they go manage those complications, and then special care. It’s the cerebral palsy patients that get special care. Hmm and I thinks that what I (mumbles off).

I: Mkay, and so do you have any other comments about near miss um for babies and their care and just anything in general you think is important for us doing this research to understand? That we may not have like covered.

P: Any comments, no.

I: Ok, well again thank you for your time and for answering our questions. We hope you answers will help us understand more about why babies that seemed as though they would’ve died, live instead. Please let me know if you have any questions.

P: Sure.

I: If you have questions in the future I can be reached through \_\_\_\_\_ and she will have my contact information. And you can also ask her questions as well.

P: Ok. Thank you.

I: Thank you.

END OF INTERVIEW

Type: HCP Interview-KB9003

Date: 25-6-15

Position: Doctor-Junior Resident

I: Alright so…ok um so thank you for taking the time out of your busy schedule to meet with me today. Uh so as I’m sure you’ve been told uh this project is focused on learning more about babies who have life threatening complications during and after delivery, but who survive. Your thoughts and opinions about why some babies survive while others die are very important to us understanding these issues better. So as a reminder, we’ll be recording the interview. This is just so I have something to help me more accurately remember what we talked about and I won’t have to take as many notes, I’m really just taking notes on what to follow-up on that you say.

P: Ok.

I: Uhh and just so you know, the recordings will never be played publicly. We will transcribe them and then destroy the tapes.

P: Ok.

I: If there is anything that you don’t want to talk about, please let me know. Also, we can stop the interview at any time. Please let me know if you would like to stop.

P: Ok.

I: Uhhh what we talk about will remain confidential. I won’t share the details with patients or others at the hospital. You will not be named in anything that is written about this research.

P: Ok.

I: And just so the tape knows, which interview this is, it’s KB9003

P: Ok.

I: Um, so we would like to learn more about your experiences with babies who are ill and their outcomes.

P: Ok.

I: You’ve been working on this NICU for about a total of \_\_\_\_\_ now.

P: Mhmm (/yes/)

I: Um some of the babies have had severe complications. Some of them, you may have struggled with and they died. Some of them, you may have struggled with and they lived. Some died no matter what you did. Uh some lived when you thought that they would not have lived. What do you think was the difference between those who lived and those who died?

P: Um, to a large extent, money…money is what made the difference because ehm it’s what determines whether the medications you prescribe are going to come; whether, whether the lab investigations you want don are going to get done, so to a very large extent I’d say money is the is the first thing. And then…um, yea, it comes down to money, so its money.

I: When you say money, do you mean…money the hospital has?

P: No, money that the eh parents have. So most of the babies are brought to us without parents cause maybe mom had a CS or delivered in another hospital and baby was referred here. So baby would be brought by maybe healthcare personnel from that hospital and sometimes an accompanying relative but most of the time they don’t have money. If you write investigations for them, you want them to do some basic tests and you eh it wont get done because there’s no money, the parents don’t have money and cant afford to get most tests done. If you prescribe medications ehm, here at NICU we have a revolving fund so at least there are some basic items that you can start off with, ehm whilst you wait for them to buy to replace but ehm if they would have to go and buy it on their on or ensure that it gets done, it doesn’t get done. Most of the time for those who don’t make it, yes.

I: Mhmm, and so for like let’s say a mother or family that doesn’t have the money, are there other things you’re able to do for those babies? Like let’s say they can’t afford that medication, what usually ends up being done?

P: So, sometimes we would ehm [cutout-3:38]. And even as healthcare workers ehm make a donation and try to get that sorted out or contact social welfare if possible and they can like give us a letter to waive some of the bills off uh huh so that we can get it from the pharmacy on credit for the patients here. So such arrangements exist but it’s eh quite bureaucratic, it takes a lot of paperwork and also, I mean, if it’s taking out of your own pocket there’s only so much that you can give at time, so these are the challenges with it.

I: Uh can you tell me about your experiences with those babies who lived when you thought that they were going to die? What diseases or conditions did these babies have?

P: Hmm…ok so um…those with severe birth asphyxia. There’ve been a couple that have had like been severely asphyxiated, had seizures; just were not doing well at all. We had to keep resuscitating and somehow they they pulled through and I think some ehm for some of them what made the difference was ehm for that for example, if they seized breathing there was somebody available who caught them that they had stopped breathing and drew somebody’s attention to resuscitate the baby. And ehm if we monitor their blood sugars as we were supposed to we would catch the hypoglycemia before anything bad happened. Uhm we needed ehm parents to be available to help us to get an ultrasound—transfontanel ultrasound—done we could be able to get that done. Ehm have them to have ehm labs like ehm assessing renal function that could get done, that got done. And so everything that otherwise would have slipped through the cracks sort of ehm was sorted out and then baby made it. So, yea for me on the top of my list that would be severe birth asphyxia. Those are the ones that surprise me made it because somehow something worked out.

I: Mhmm, so uhm, is there any special care that are given to these babies after their condition resolves so after their resuscitated is their special care that their (loud speaking in background increases rendering end of sentence inaudible)?

P: Special care…in terms of like when they are discharged or ehm still in the hospital after their acute episode?

I: Both.

P: Ok, [cutout- 6:32]. So still in hospital then ehm whoever is covering for the day gets eh special notification that lookout for this baby and it gets handed over verbally during the handover and when the shifts change. And…it depends on what state they are discharged home in. For some of them, ehm by the time they are going home they are well, everything is fine they don’t need to be rigorously followed up. For others, if eh they’ve been here for long and its protracted and ehm we are discharging, them they’re stable but they are not like, you know, fully well we give them a shorter interval for reviews and they come more frequently for review so that’s the kind of follow-up, I guess.

I: Mhmm, so are mothers typically given special instructions for caring for babies that lived even thought they looked like they were going to die?

P: Yeah, ehm I, every baby that we discharge from here, well its assumed that all the babies that we get, most of the babies we get are ill are very ill, so when they are being discharged they may get special instructions. It’s not written down but they are taught ehm what special things to look out for. We counsel them during the course of their stay here for example those with asphyxia that we anticipate may have ehm developmental delays or if they are preterms and they at risk for certain things we counsel them about it and prompt them to look out for them before they come. For example if they are preterms and they are going home and we’re afraid they may have apneic episodes we tell them and so they know what to look out for and where to seek help. Not necessarily coming back to\_\_\_\_\_\_\_\_, but any health facility nearby, yeah. And I think in recent times also we have a form we fill for those that have been referred from somewhere far or that are going back to a community where there is a pediatrician, there’s a specialist to follow-up; we give them eh a written eh referral that states what their problems are and what needs to be followed up and how often they should be followed up, yeah.

I: Um, do mothers usually understand like all instructions that are given…for the special care for their babies?

P: I think so because ehm, it’s given in it’s it’s a verbal discussion that’s had and it’s in a language that they understand so opt. If its English they understand, its English, if its in Twi, its in Twi or Ga and if none of us speak their language we make sure we find somebody who speaks their language and then ehm have that person translate. There may be some things lost in translation using a third person but generally they should’ve gotten an understanding of what of what what has been [cutout-9:26].

I: Um, so when moms don’t understand, what is usually the reason why? [cross talk] If, I mean if you feel like, if you’ve ever encountered a mother or mothers that didn’t understand what is usually the reason why? Or if they didn’t do what they were suppose to do. [cross talk]

P: Suppose to do, oh ok. Um I think sometimes not very often but sometimes they’re when they’ve been at NICU for so long and finally we are getting to go home they are excited about going home so I mean they will say yes to everything that you say just because they know that means after this formal talk or whatever instruction, I get to go home with my baby. So they are excited, they want to go home so they they nod yes to everything and say they understand everything that you have said whilst perhaps they didn’t really understand everything that was explained. Yeah so sometimes it’s because they are inattentive as in like I said so they they really didn’t understand even though they said they did understand, uh huh.

I: Ok, I know we talked about like language could be a potential barrier, do you can you think of any other potential cultural barriers that might exist to giving like instructions to the mothers?

P: …Cultural barriers…hmm…none that I can think of.

I: That’s fine. Um have you ever discussed one of these cases of babies that survived when you thought they wouldn’t with your supervisor?

P: Oh yes, yeah yeah yeah because…(person comes into room to ask question)

I: (speaks to interrupter from 11:06-11:48) Uhh ok so yeah have you ever discussed cases like this with your supervisor?

P: Yeah, yes, yes ehm because they surprise us. It’s it’s like you don’t expect, you think that oh they’re not going to pull through and then they do and then you wonder what made the difference. Or if there is something you missed and so made you think they weren’t going to make it, so yes we do. Sometimes we even present them at our mortality meetings or we have case presentation from the various wards and [cutout-12:21] those cases so everybody else knows about these cases, yes.

I: Mhmm, um so what members of your team tend to bring these cases up to talk about them most often?

P: …Um…no one in particular, its not left to like, eh…I mean once you find something interesting about it, you either share with another resident or the senior resident and then discuss with a consultant and if we think that oh there was a learning point there then we transfer to the morning meeting and then the whole department hears about it in our morning meeting so there’s no particular cadre of people that will bring up those issues, it’s if and when.

I: Mhmm, ok. Um, so when you end up discussing these cases, what is usually the outcome of the discussion?

P: (coughs) Sorry (coughs). What’s the outcome?

I: Yeah, the outcome of the discussion.

P: Mmm, I guess at a few times I mean if really there is a learning point there, it it gets discussed with the general department. Ehm, other than that it’s yeah, it’s just something that we share amongst ourselves just to know that oh, somebody made it that we didn’t think was going to make it, yeah.

I: Uh, have you ever received formal training on how to handle these kinds of cases of babies that survive when you thought they wouldn’t have?

P: …No, no, no, no.

I: Um, do you think there should be more training on how to handle these cases?

P: As in ehm, babies with asphyxia or babies that we think generally would not make it but then make or?

I: Like babies that like you said, “Oh this baby is making it, I thought it wouldn’t.”

P: Mhmm.

I: Do you think there should be some training on how you should go forward with that kind of baby?

P: …Hmmm…sorry I don’t think I understand what you are asking.

I: So, um, like when a baby is surviving and you knew that it was very ill…

P: Mhmm.

I: Do you ever think that you wish there was something else that you knew to do to make sure that baby still survived?

P: Oh that ehm, like special training in terms of ehm…like you’re saying something that you could do better or something you could’ve done earlier in order to ensure that baby made it?

I: That they keep making it, like its like ok this baby is living and now I should do this to [cutout-15:15] go on.

P: I think that’s like with general practice like I mean in your day to day work. Er if you have an ill baby with your reviews everyday, you pick up on things, vital signs and things that you should be looking out for that will prompt you that baby is going downhill or baby is stable or baby is actually improving. So ehm I don’t think there’s a need for like some special training. I don’t think there’s eh I don’t know what form that would take because that that’s just a ?(share)? as part of your training as a doctor and becoming a specialist. You work with these babies and then you sort of learn to pick up on subtle cues that point you to an ill baby or a baby that’s stable. I don’t I don’t know if I answered your question, hopefully but…

I: Well, here, I can give um an example, I don’t… So like for instance, let’s say you had a baby that asphyxiated but they survived, like some people say, “Well maybe I should start paying attention to certain kind of organ damage but I wasn’t, I’m not trained on that.” So like those kinds of trainings that follow-up on other potential things that could cause harm for a baby that almost died.

P: …

I: But do you feel like you are already trained on that?

P: Yeah, I think so, I think so.

I: Ok, um what do you believe is the most important thing to understand in order to handle these kinds of cases of babies that almost died but they lived?

P: …Sorry, what do I think is the most important…?

I: Yea, just the most important thing to overstand, to understand overall.

P: …I don’t, er to understand about what?

I: About how to take care of these babies.

P: About taking care of the baby… hmm (long pause). Ok, repeat the question, I’m thinking, I really don’t…

I: It’s okay, what do you believe is the most important thing to understand in order to handle these cases?

P: …Um, I think if if that like there are always signs, there are always things that point us to the fact that a baby is very ill or baby needs special attention and you should always pay attention to those things and they are basic things. Um if if we are monitoring, we are looking at heart rate, if we are looking at blood sugars, if we’re actually reviewing frequently and checking and following [cutout] and so we pickup these things. That the challenge is that sometimes we we’re understaffed, we like there are not enough people and so a baby that should get the necessary attention doesn’t get that attention because baby cannot be reviewed as frequently or baby cannot be monitored as frequently and so we don’t pick up when their heart beat begins to drop or their heart beat begins to go up or baby starts bleeding or something goes wrong. It’s always with the vital signs but we don’t pick up on that. So I think its just knowing that there’re things that like if you actually look for them you would find them, yeah.

I: Do you feel like there something that’s most important for moms to understand about their babies that almost died but lived?

P: Yeah, they ehm…For the long term or whilst the baby’s at here?

I: The long term.

P: For the long term. Ehm…yeah I mean if the baby almost died but then lived, meaning that there was some form of an insult or something, something that made the baby ill and it could be because of something congenital, it could be because of something in the environment where mom was when she was pregnant or something. So she has to know and be able to look out for those things as baby is developing. I mean, if it is going to have an impact on the baby’s development and all that, she has to know. Know that to look out for those things…and be able to pick up on them.

I: Yeah, ok. Are you familiar with the term near miss?

P: I think I heard it, ehm yes I know near miss as in the eh the eh…like how what it means literally in English and also with regards to this study because I think there was a presentation on it once about what was being done with the study to find out when which babies would have died but then made it so they are, they were nearly missed I should say that, yeah ok.

I: Yeah, uh so do you think mm all providers all have the same idea of what a near miss is?

P: Providers in terms of?

I: Like healthcare providers.

P: In general or specifically doctors or people who work—

I: In general, so including nurses, any like anyone dealing with these babies, do you think have an idea of what a near miss is?

P: It’s hard to say. It’s hard to say. It’s hard to say, I don’t know.

I: So, some may not know the word near miss.

P: Mhmm.

I: But would you say like “Oh ok, this baby is ill and there’s this baby that was very ill and almost died but they lived,” like this, you know, kinda categorize them even though they may not use the word near miss? Or do you think most people that work with these babies just “All these babies are ill and that’s all I’m thinking about”?

P: …Oh…I think there are some some that make the distinction between those that are…were like nearly missed. I think there are some that make a distinction, yeah.

I: And do you think that distinction is helpful to make?

P: Yeah, because then ehm it it like I said you you pay extra attention, especially in a place where you are understaffed like I’m saying if you, when you are handing over, you know that specifically this baby also has to be handed over so that somebody actually looks out and monitors and ensures that what should be do actually gets done. And if anybody else doesn’t get that kind of care at least this one will get that.

I: Mhmm, ok. So, if you knew a baby was classified as having a near miss do you think it would change how you managed that baby?

P: …I think so. I think so because then, like I’m saying, if I’m…I would consciously make an effort to above everything else check in more frequently on that baby even if I was pressed for time or something, yes. I think so (coughs) sorry (coughs).

I: Ok, what do you what challenge do you think babies who experienced a near miss will face as they age?

P: …Oh…well it depends on what caused them to be a near miss. So if eh…they have problems, congenital problems, then depending on what made them a near miss it can impact them for the rest of their lives yes.

I: Mhmm ok. And do you feel like the healthcare system is prepared to respond to whatever needs they may have?

P: No, I don’t think so, I do not think so. Because ehm, like I said earlier on, if they need to be followed up, you need to have people that are dedicated and know what to look out for and at what times ehm, these visits should be done but if th-there’s no real structure to it, then everything just falls, goes down the drain.

I: Mhmm, do you have any other comments about near miss babies, um that you think will be useful for us to know for this study? Just anything in general that you think will be important for us to understand.

P: …I think ehm sometimes…Some babies just…are in the ehm right place at the right time. That’s that and maybe you’d put it down to luck or or something good fortune because you imagine that if this baby had maybe been born in say another facility that didn’t have a certain equipment or didn’t have a certain expertise of staff then there’s no way this baby would have made it. So sometimes I think where you are born and where you find yourself at a particular point in time makes a difference between you becoming a near miss or actually getting missed, uh huh.

I: Ok, well thank you for your time and for answering questions. We hope your answers will help us understand more about why babies that seemed as though they would die end up living. Um please let me know if you have any questions.

P: Ok.

I: If you do, you can contact me via email or Dr. \_\_\_\_\_\_ who has my email.

P: Ok.

I: Ok (removes microphone).

P: Thank you.

I: Thank you!

END OF INTERVIEW

Type: HCP Interview-KB9001

Date: 23-06-2015

Position: Nurse

I: Ok. So uh thank you so much for taking the time to do this interview today I know you you are about to leave after this. Umm so as we discussed, this project is focused on learning more about babies who have life threatening complications during and after delivery but who survive. Um your thoughts and opinion about why some babies survive while others die are very important helping us understand these issues better. Um as a reminder I will be recording the interview. This is just so I have something to help me more accurately remember what we talk about. It also that means I don’t have to take a lot of notes, I’m more so just writing something to follow up on later. Um just so you know these recordings will never be played publicly uh we will transcribe them and then destroy the tapes. Um if there is anything you don’t want to talk about please let me know. Also we can stop the interview at any time. So please just let me know if you would like to stop. Um what we talk about will remain confidential, I wont share the details with patients or others at the hospital. You will not be named in anything that is written about this research. And just so the tape knows this is KB9001. Um ok so now we are starting the interview. Um do you have any questions before we start?

P: Your name.

I: Oh I’m \_\_\_\_\_\_\_\_\_\_, I’m sorry. And your name?

P: \_\_\_\_\_\_\_\_\_\_\_\_

I: Oh, well, I will take that out, sorry (laughs).

P: (laughs) It’s ok.

I: Um we would like to more about your experiences with babies who are ill and their outcomes. You’ve been working on the NICU for \_\_\_\_\_\_\_\_\_\_ now. Um some babies have had severe complications. Some of them you have struggled with and they died. Some of them you may have struggled with and they lived. Some died no matter what you did. Um some lived when you thought that they should not have. What do you think is the difference between those lived and those that died?

P: Well, it depends on the prognosis of the babies’ condition. If it’s very poor, if we can see baby not breathing so well, baby has to be AMBU bagged for hours and eh when baby, baby has been AMBU bagged for a while it is better to use the CPAP. This is a machine that kind of AMBU bags the baby, pushes air into baby’s tummy, kinda helps baby to breathe. So we put baby on that connected to oxygen. Baby stays on that til we know baby baby can breath or when we are checking baby’s ehm oxygen rate, the blood oxygen level of baby, and it’s about about 92 percent. We know baby can do better off the CPAP. So most babies come with very poor prognosis. They might not survive. Others do survive. It depends, mostly they the males don’t survive as much as- ehm, the number of males who may survive are less than the number of females who survive. So…

I: I’m just making sure this is (checking that recorder is working) ok. Ok, um…what do you think is the reason females tend to survive more?

P: Well just like ehm, just like conception. Females, females are faster, stronger. Female genotype is more stronger than the the male so it eh tells what happens after they are out. The females are able to survive more than the males. So that’s the whole thing.

I: Ok (noise from the background). So can you tell me about your experiences with babies who lived when you thought they were going to die? Um what diseases or conditions did these babies have?

P: Well there was an instance we had a baby with eh baby was preterm and ehm yea preterm. Baby came with prematurity. And when they come like that they have to be kept warm they have to be kept warm and then ehm we have to make sure they are breathing. When they are not breathing well enough it doesn’t. When they are not able to take in more oxygen then they are depriving their body or the brain. For some parts of the body from getting oxygen and it will cause brain death and whole lot of organ death. So this baby came was preterm, we kept baby in an incubator ehm to keep baby warm. And then ehm when they are preterm to you don’t you don’t bathe them so often cause while you are bathing you cleaning the the oils the body produces to protect the skin from, protect the pores of the skin from opening to the environment there by losing heat to the environment. So here we we bathe babies twice in the week. To kept them, the eh heat in them so uh we keep these babies we keep this, we kept this baby in the incubator, bathing baby twice a week, and we had to do feeding by NG tube, that’s a gastric tube; it feeds baby gradually. Sometimes you have to start with very small amounts of feed from about 2 mils (/mL/) and then it increases gradually as baby can tolerate feed. So we did that for baby and baby deteriorated at a point, like oxygen rate was low, we had to restart oxygen on baby. We had to do what we call gavage feeding, we put the feed in ehm a perfuser and then it’s all calculated the number of the number of milliliters it takes to flow to baby. It is a very gradual process, can last for about four hours. So the feed is put in a big syringe and put in the perfuser and it allow to feed baby gradually. This is what we had to do when we realized baby was vomiting after feed. When we were doing the nasogastric feeding. So we had to switch to the gavage feeding. And baby did well, we started we so we switched back to the NG tube feeding, baby kept doing well and then to cup and spoon. We allow mother to [cutout-6:32] cup and then feed baby by spoon. Baby was doing well so baby was brought in here to the KMC room. Mother ties baby, so mother kind of continues giving the moisture baby missed from the womb because baby wasn’t wasn’t a term baby. So mother keeps tying baby in front of her to give moisture eh warmth to baby and baby’s gone home. Mother came around baby for review, baby is doing well, she is gaining weight, gradually, so some do survive.

I: Ok, um so… usually like with babies that you thought were going to die, and they lived is it usually just that you kept trying or do you feel like there’s usually something that’s done that usually ends up being the reason that they live?

P: There’s a protocol with the ehh treatment. First of all when you are, when you realize baby comes, baby is preterm, baby is prone to infection for the fact the baby is preterm. Baby doesn’t have a strong immunity against diseases. So immediately we start giving baby some prophylaxis to keep baby from getting infections. So antibiotics are started on baby at a point and and over here mostly baby might be paired in a court. ‘Cause we don’t have enough court, and this is like the the the biggest hospital in \_\_\_\_\_\_. So all are transferred here and you can’t tell they don’t want to take anymore. And here the case is the place is that small, so we end up pairing babies. And a baby might pick infection from another because we are pairing. Though we change gloves in between babies, we wash hands in between babies. We finish everything collective on a baby before move to another. But sometimes infections do cross. So if a baby we realize babies on prophylaxis and babies ends up with an infection or baby’s baby’s deteriorating then a higher antibiotic would have to be used on baby. This particular one I was talking about were given some antibiotics, realize baby, baby was paired with one baby who passed on. And I think the next day, baby baby started vomiting after feeds, so antibiotics were changed to a higher one. Baby was transferred to a different incubator alone and we cared for that baby and baby survived. So we we actually check ehh our treatment as well and then any intervention that will help baby to survive we put all in place.

I: Ok. Um so are usually any other special care given after the patient is resolved?

P: Any special, let’s see. Whilst we are on a particular baby we involve mothers. So as we we care for the baby, mother is educated on what to be doing for this baby. Let’s say if mother is feeding baby, mother is educated not to and and mother is doing cup and spoon, not to fetch feed and pour into mouth baby’s mouth. But she would have to take her time for baby to lick the feed from the spoon on her own. So then that way baby is not going to get choked. So mother will help with, mother will also learn what to do and then we will all end up achieving ehm like getting baby to get well and not deteriorate in health. So not ehm any any special care after they make it but we involve mothers in the care so they kind of continue what we were doing. So that’s it.

I: Ok. Um so are mothers typically given special instructions for care for babies um that live to survive but once they’ve been discharged?

P: Yes, they they are, we educate them on the feeding in particular, on personal hygiene, and then eh on any danger signs they might note. If baby is spiking temperature, baby’s temperature is getting higher and higher at home, mother is advised to come immediately. Mother shouldn’t go buying any medicines from anywhere ‘cause baby is preterm. So mother is advised to come to hospital immediately. And then ehm yeah, personal hygiene for the mother herself and the baby as well and then anyone who might come into contact with baby. We mostly advise them not to expose baby so much to the public. Most people go home and they getting lot of visitors to come and see baby. We advise them not to encourage that. They keep baby inside just like they were here, til baby gains enough strength and builds more immunity and we encourage them as well to breastfeed. That helps baby to get eh good immunity against any infection. So.

I: What cultural barriers do you think exist for giving good instructions to the mother?

P: Umm…as in how well they accept instructions?

I: Mhmm (nods yes).

P: Well here most mothers are I think most mothers come in and they just look at you, your size and they’re like, that’s a little girl, giving me instructions. We we actually we’ve been on the job for a while and we know what we will be teaching you. So we wouldn’t just get up and say just give instructions from nowhere like do that or do that. So most people think they are older or maybe you can’t just come and give me instructions. It’s okay they been on their own they live on their own they buy their own stuff so at a point they are in here and we are telling them “go go wash your hands, Have you washed your hands after changing diaper? Have you done this?” It’s like you really instructing them but its for their own good. Some some you might forget, you got you got a lot on your mind you are thinking of your baby you’re thinking about your sleep you are now off from the you have been discharged from the ward you had to go home and back every time and it’s a lot of things for them. So sometimes we kind of remind them but some may take it like you are instructing me so much uh huh. And and and they try to tell their doctors well baby is okay, discharge me let me go home. But when we get there we assess baby and is not for your own good it is for baby’s good. So we assess baby, baby can’t go home you keep staying. So.

I: Ok. Have you ever discussed one of these cases of babies that survived when you thought they wouldn’t with your supervisor?

P: Yeah yeah I have. This particular baby I was talking about, I was actually talking to one of my doctors that that baby survived oh was really fast. We all thought baby wouldn’t make it. ‘Cause when they other baby by her passed on, mother was in tears. I called mother aside and told her the fact that the other baby passed on doesn’t mean her baby will pass on. She needs to have faith and just along with what we teach her and do it well and today baby is fine. So we were discussing we were really surprised baby made it, ‘cause baby baby gradually lost weight. Baby’s birth weight reduced so we had to then kept weighing baby every time, check the feeds so that’s how come we had to do the gavage feeding. That we know this is the quantity baby’s receiving at this time and it helped.

I: Um so are cases like this usually discussed amongst like your team?

P: Yes. We discuss it and then sometimes we try to bring out what we did that really helped baby so in case we have a similar case or something we could apply knowledge, we do. So we discuss, when, in this case, when a baby has a similar thing as the other one what do we do. And sometime we have the baby right there so ok let’s make sure feeding is well done, let’s proper let’s feed slowly, give some interval between feedings and it helps.

I: Um, what members of your team tend to discuss these cases the most often would you say?

P: All the doctors and nurses. ‘Cause we mostly together in the cubicle so as soon as I, I see a particular case I draw the doctors attention and immediately we bring our ideas. “Ok I think this was done well. Why don’t you repeat it again,” or “why don’t you observe how it goes.” And we discuss and we add on.

I: Umm, so what usually is the outcome of the discussion?

P: Uh we pick out we pick out all the positive things that were done. And then we pass knowledge on. Sometimes it’s written, it it’s handwritten all. We have it we have it documented that in such a case, this this is done, do this and it helps. So we document and we we we keep practicing it but we always take into consideration, you know every every baby is an individual. We don’t say because we did this for this it is exactly what we are going to do for this particular one. So we actually manage them as individuals.

I: Ok. Have you ever received formal training on how to handle cases of babes that survived when they looked like they were going to die?

P: Yeah, we have. We we we went through a training, neonatal resuscitation. Where in case there’s is no doctor around. I notice a baby is not breathing, I immediately check a baby’s breathing, I look I listen and I feel. Baby’s not breathing. Immediately I get my AMBU bag I tilt baby’s head back a little sometimes I can give baby a back er a neck roll we’ll put eh a sheet a rolled sheet under the neck to give baby’s head tilted back a little. So that the the airway is open, it’s patent. You check airway, you bag baby, you keep bagging baby, you check for the pulse, baby has pulse, we keep bagging ‘til baby can breathe. But you can bag with oxygen connected to the bag and it helps baby and you can call for help. So you can start that and then call for help so at least baby gets some kind of first aid. So we have been trained.

I: Mhmm. Um so do you feel like that training has been useful for you?

P: Yeah it has, it has. It was a time the doctors were taken up in the morning and I was with a colleague. I was just checking each baby and I just saw a ba- they were twins. I saw one of them the color was blue [cutout-18:11] (describes one baby as blue and the other is pink) pink. I could see so easily, then I drew my colleague’s attention. And she immediately brought the AMBU bag, we suction baby immediately, we bagged baby. By the time the doctors got to our end, baby was breathing so we just told them about it, we document it and then we followed up. But unfortunately the babies passed on. Yeah those babies, the one we bagged first passed on and I think after three days the other dead. I was sad anyway.

I: Mhmm, that is sad. Um, so do you think there should be more training on how to handle these kinds of cases?

P: There should be more training, frequently, frequently. Let’s say every every two or three months we do. So we refresh our memories and our trainings we share experiences and we learn. So there should be more trainings.

I: Mhmm, is there anything in particular you feel like should be added to the training?

P: Mmm… (extended pause) Everything has always been touched anyway, they never leave anything out. But it’s okay to keep refreshing us on it. Sometimes you might get used to a particular procedure. And might add what you shouldn’t add. You think if I do it this way, it works. But it’s not documented you haven’t had any research on it. So we can’t say it works and I keep doing it. So if truly it works, then we have to carry a research on it and add it to our protocol. So mostly when we are refreshed, you get to kind of have a fresh idea, this what I should do. Even if that works, I should really have a good experiment on it before applying. So we should always be refreshed on most of our procedures. It helps.

I: Mhmm, ok. Um, so what do you believe is the most important thing to understand in order to handle these kinds cases of these kinds of babies…like just like overall? Like what should you

P: You should always be, you know the babies wouldn’t talk, this has happened to me. You should always be very vigilant. Always eyes open, ears open, you should be very vigilant. Just looking around. We have this sanitizer in a bottle, when it’s pressed it sounds like a baby choking. Yeah, it goes, it has this sound like a baby choking and I I I know that sound. So anytime its pressed I look around, what is happening, which what is happening to eh which baby is it? So I realize it was the sanitizer so I drew one of the doctor’s attention to that. “This sanitizer, anytime you press it it sounds like a baby choke.” And she said, “Yeah it does, it sounds like that, how did you know?” I said, “I’ve been listening.” So you need your eyes wide open you look and look well. If you can’t, you are not sure, you go further and then check well. So we just have to be vigilant, babies won’t talk that “I need this” that “I am chocking” that “I wee-wee” or anything you just have to be vigilant.

I: Mhmm. So are you familiar with the term near miss?

P: No, I’m not.

I: Ok. Um so uh a near miss is what we’ve been talking about so like when a baby really seemed like it was not going to make it but it does so we just it just made it. So that what we call a near miss.

P: Ok.

I: Um, do you think like health care workers have, all have the same idea of what near miss is?

P: I, I can’t really tell. Like you asked I didn’t know what it was, uh huh so. I wouldn’t know how many of my colleagues would really understand as soon as you mention it. So.

I: Yeah, ok. Do you feel like um, in their mind they think differently between babies that come here that are sick and babies that come here and look like they are not going to make it and they live. Do you think that they actually kinda separate them out from other babies or no?

P: Sometimes you do. Sometimes we go home and come back and like “wow this baby still here” and like “yeah baby still here, baby is making it.” Today we mentioned about we talked about one baby, the doctor said, “Hey this baby is really strong, I thought baby would’ve died by now but baby is still alive.” So it it happens. People mostly mention, they they kind of separate them like they think this baby this baby not going to make it this one won’t make it. And the next time we come, the one we thought would make it is rather gone. So at times we do it ourselves.

I: Um, do you think like separating that out as a healthcare worker is useful?

P: Uh eh (/no/), it’s not. Even if you think baby might not make it you still have to give all the necessary care to baby. You might think it but do your best for baby. If baby is gonna make it, it it’s fine if not, then you know you you did your best, so its not a good idea to just assume it and then not perform.

I: Mhmm. Do you think seeing that a baby that looked like it wasn’t, might not be making it could make people more ehm…work harder? Or do you think it like you said it will make them work less?

P: Yeah, it will make us work harder.

I: Ok.

P: You think baby is not making it. And baby has, doctor has [cutout-23:57] let’s do this for this baby, do that do that do that. You’d want do it, let’s see how baby would do. Let’s help baby. Every body wants to help the baby, so we we are most of the time we are all on board. Even though we might think this baby might not make it, but everybody is on board, helping baby to make it.

I: Mhmm umm ok. If you knew a baby was classified as having a near miss, do you think it would change how you managed that baby?

P: …Uhh you give more attention anyway. You give more attention. We have one more baby like that. Eh, we have a, they are twins too. A male and female. The female here, in this case, the female always deteriorating. I was feeding baby, baby was came preterm, both came preterm. They were doing well eh on on parenteral feeding, that eh IV feeding and stuff. And then they moved to the oral feeding. We we had the nasogastric tube in and then we were feeding. Baby were babies were doing well and mother moved to the KMC room and was doing the feeding herself, she was doing fine until once baby aspirated. And baby was brought back to the ward, we kept managing. And once I was feeding by the NG tube, I give intervals, say I feed this one eh 5 mils (/mL/), I leave her for about fifteen—five minutes or ten, then come back to feed another 5 mils (/mL/), which I do very slowly. I move to another baby, by the time I turn to the that baby, baby had vomited. The mouth and through the nose, so I had to suction baby immediately. Baby’s breathing, baby’s chest movements were slower, so immediately I, I ,I give oxygen to baby. I checked oxygen rate, it was oh it wasn’t so low but baby’s chest movements was was not that…frequent. So we we kept suctioning, we stopped baby’s feed, we put baby on parenteral feeds and baby started doing well. Went to mother and went back to the ward again. That was Sunday, baby took out her IV line was bleeding. We had to transfuse baby and the feeds was were given, this time baby was able to tolerate feeds. Eh baby’s alive, anyway, baby’s still alive and ah mother mother said baby was troublesome. I said no, she shouldn’t say that, she should treat baby as baby wouldn’t have if baby didn’t do all this, she should keep treating baby very nicely. She gives up on baby, baby dies. This is what I have noticed: when parents give up on the babies, the babies die. So we encourage them not to give up. Even if they see that really baby is going, they still shouldn’t give up ‘cause their faith can do something. So that baby that baby is still alive, I think they are still in KMC. Mother mother mother doesn’t seem so confident in their feeding ‘cause this thing keeps reoccurring. But we keep encouraging mother cause she can’t stay here forever. So baby is doing well.

I: Mhmm, that’s good. What do you think usually makes mothers want to give up on their baby?

P: When they think they are doing their best and babies keep deteriorating then, “What am I here for?” But we keep mothers, we keep telling them not to give up. We encourage them not to give up. We encourage take more rest, just relax them and think of some happy moments. The baby is in yes. If baby if you had given birth to a term baby, you just go home and you are happy. So probably you didn’t plan for this, no one would ever plan for this. But as it’s just happened and we encourage you do your best and definitely you move. So when babies are not doing very well, as mothers are putting in their best, mothers tend to give up on the way. And sometimes mothers might not be doing exactly what they are instructed. That is why baby might be deteriorating so we again educate them on what to do. And we observe them do what we educate them to do. So we know they are really doing what we want them to do. So in this case, mother when mother is brought back to the ward, we supervise her feeding of the baby ‘cause it’s the feeding that always chokes baby and mother will rush baby in. So we keep supervising mother and encouraging her to do it. She shouldn’t get scared of feeding baby. And she she keeps doing it, so reeducation will keep them, even though they feel like giving up on the way. And we we really do that, we really do education every time on the babies.

I: So when moms are like getting ready to take these babies home that almost died what do you think is a factor in these babies surviving long term once they’re home?

P: Oh once they are home, it depends on how well mother, mother really puts up with all that we said. Do this, do this for baby, when this is happening, do this for baby, especially when baby has a temperature, don’t don’t bother yourself (stutters) [cutout-29:44] and tepid sponging baby. You kind of wipe baby with a wet towel, lukewarm water. Some baby’s baby is very small, so we let baby lose even more heat though when you use lukewarm water. But the body the body adapts to it gradually, than using cold water. Baby will cool off but the mind will read cold temperature from the body and then will stimulate warmth to be, to come and then baby will get hotter again. So it’s better to do the tepid water sponging. But we advise them to come immediately, as soon as you see baby not doing, baby is not feeding well. You know when they, they start to spike temperature, feeding drops, they wouldn’t feed well, they won’t be [cutout-30:29]. we educate them how a healthy baby should be so when they see the the negatives, immediately they should come. We don’t mind taking good care of them, that’s our job, that’s why we are here mhmm. So that helps. When we educate them, and they accept it well, they they do it as we we educated them. They perform it well and they go home they keep do they keep at it and then they come for reviews. So during the reviews we assess baby, how baby is doing, and then we reinforce on all the teachings we give them before they are going home. And then also try to address any problem they might have at home and help them solve them. So babies end up surviving, well I haven’t seen a preterm baby who has been who was here say seven years ago or something, ‘cause its just three months since I started working here. So but I’m sure my my seniors who’ve been here for long, might give such examples.

I: Mhmm, ok. What challenges do you think babies who experienced a near miss will have as they get older?

P: …Oh… I can’t really tell. I can’t tell. I’m sure as they they mature they will just be fine. There wouldn’t be anything like because you were born preterm and you were sick and you almost died, anything at all can happen to you. I don’t think so. They will they will they will be fine as any normal person, so I don’t think that would effect their life.

I: Ok. Uhh ok that the most of my questions. Um do you have any other comments you want to make about babies that almost died but survived, just in general, just for the study that we are doing?

P: (long pause) Nmm mmm (shakes head no), no I don’t.

I: It’s okay if you don’t, its just in case you had something else that you thought.

P: No, I think I said all that I’ve observed. Its been quite short time but I I’ve always tried to get myself to the the hectic side just to learn faster and now they keep me there, so if I didn’t learn fast I would’ve been in trouble (laughs).

I: (laughs)

P: So it helped.

I: Well it’s good that you are learning quickly. Umm so well thank you for your time for answering these questions, we hope they’ll help us understand more about why babies that almost died ended up surviving. Um so do you have any questions?

P: Um…Ok your you team, do you guys have anything you [cutout-33:23] after you are done with all this project?

I: Um well it kinda depends on what we see…

P: What you collect.

I: Yeah, like if we find something that is useful, of course, I would assume it would be shared with the hospital as in so Dr. \_\_\_\_\_\_\_, who works here, um would you know make sure you all knew and then the work gets published. It’s almost just like what you said like we can’t just tell you that this stuff works it would have to be like

P: Yeah, yeah.

I: Oh the research has shown that this is what was seen. Uh so yeah we would make sure it would go through the right process to get into a protocol if we found something useful.

P: Ok, ok.

I: Anything else?

P: No.

I: Ok. So if you have any other questions you can talk to me. I’ll actually make sure to when um I bring you a copy of this form (referring to consent form) to put my contact information on there and Dr. \_\_\_\_\_\_\_\_’s contact information on there. I don’t know if its already on there, it might be. Um so yeah, that’s it.

END OF INTERVIEW

Type: HCP Interview-KA9007

Date: 30-09-2015

Position: Doctor-Resident

I: Ok thank you for taking the time out of your busy schedule to meet with me today. Uh, as I’m sure you’ve been told, this project is focused on learning more about babies who have life threatening complications during and after delivery, but who survive. Your thoughts and opinions about why some babies survive while others die are very important in helping us understand these issues better. Uhh, as a reminder, I will be recording the interview. This is just so that I have something to help me remember what we talked about. I also will have to take as many notes, more so just notes so I know whatever I need to follow up on. Just so you know, the recordings will never be played publicly. We will transcribe them and then destroy the tapes. If there is anything that you don’t want to talk about, please let me know. Also, we can stop the interview at any time. Please let me know if you would like to stop. What we talk about will remain confidential. I won’t share the details with patients or others at the hospital. You will not be named in anything that is written about the research. And just so the recording knows this is interview KA9007. We would like to learn more about your experiences with babies who are ill and their outcomes. You’ve been working on the NICU for \_\_\_\_\_\_\_\_ now. Some of the babies had severe complications. Some of them, you may have struggled with and they died. Some of them, you may have struggled with and they lived. Some died no matter what you did. Some lived when you thought that they were going to die. What do you think was the difference between those who lived and those who died?

P: Ok maybe it’s more about like how sick they were before presented, you get it. And I think normally for this unit, our patients are mostly birth asphyxias and preterm with the very low birth rates yea. So the severe birth asphyxias, it depends on how bad: whatever caused the asphyxia the primary resort was the brain, you get it. That’s how I think; it depends on how bad it was the primary resort was to the brain. And then one issue, you know we don’t’ really offer respiratory support here. When you come with respiratory issues, the person diagnoses the bag mask ventilation. But you know how like the ventilation is for the neonates so basically they just bag so that they are able to breathe: they start breathing themselves, they start breathing themselves as soon as we start ambu bagging for them. Yea so that’s one major issue, the respiratory issues with them. Most of them or both the severe asphyxia babies and the preterm too, and the preterm too if you come you know like I think if others are like 23 weeks but here is 28 weeks, that’s the cut off for admission. Even like some of the caretakers when you respiratory distress and all, and they are supposed to check, it’s just oxygen we give them. It could be the last resort but if for some reason like I can’t predict so like with the distress eventually, they get tired due to failure and die. So I think it’s depends on how it is or how bad your asphyxia was. That’s basically it to be it because we don’t do much. Just supportive care: oxygen for the preterm, if you have distress and this factor and we just give you oxygen so you cope with the distress resolve and gets better. But if it gets worse and it goes to respiratory failure, then I think there should be nothing for you. As for the asphyxias too, if you come up big, that’s the bad aspect of the patient. Hopefully if we are able to pick up, so it’s not a respiratory, it’s mainly the asphyxia babies and preterm those are our major causes of death. And so the bilirubin encephalopathy too that’s severe neonatal jaundice. It depends on how lie how as far the jaundice is, usually it can wait for neological life, when they come pestering, they are not feeding well, like it already affected the brain, we are supposed to like an exchange for them. But some as I said experience respiratory arrest, they also die. But asphyxia: some too they can they are not even stable enough to start the exchange blood transfusion. So I think it basically how bad they are presenting their issue, you get it how sick they are. I think that’s the major determinants of the outcome, yea.

I: Can you tell me about your experiences with those babies who live when you thought they were going to die? What diseases or condition do these babies have?

P: Ok so as I said, it’s severe birth asphyxias, severe birth asphyxias can probably they quickly came in from labor ward. After birth, they resuscitated at the labor ward and then they brought to us. Maybe apneic or a very few breath, or even the bag mask ventilation, at times for hours, some nurses bagging them with the ambu-bag for hours. And some it looks like they have their: they start breathing at some point yea. So I think those are some of the miracles maybe probably I’ve seen, like those who come not breathing, we bag them for so many hours. But even then am sure some may even have some neological damage as they grow up but at least for this period, we are only keeping them. You know for the bad jaundice my friend was this: he had this case of severe neonatal jaundice. The mothers never examine the baby for jaundice when they go home and they are in a very dark room. So the mother didn’t see the jaundice early so most of the time they come to us for help when they have a review, very ill, it’s obvious the jaundice is already affecting the brain. Like we have evidence of bilirubin encephalopathy, some even come and they are not even breathing. But we still go ahead with the blood: exchange blood transfusion because like if we don’t do the exchange blood transfusions they will die on the way. And even with that they also have parent who is sick to have that procedure, so you’ll probably so a small volume exchange for that period of time. And some of them amazingly, some of them make it yea yea.

I: ok erm <cross talk>

P: we have a couple of preterm too like 25 week preterm 24 weeks preterm some of them also make it, yea.

I: Ok, is any special care given after the disease or the condition is resolved?

P: Yea so like asphyxias, the bilirubin encephalopathies, they still may like some may have: some may have neological damage as they grow up. So most of the time they come to the consulting room maybe after 2 months, they are still seen by the hematologist but after that they refer them to the neology clinic after that too they do the follow-up at the neology clinic for the birth asphyxias, bilirubin encephalopathies, yea.

I: Are mothers given special instructions for caring for babies that live that you thought were going to die?

P: yea, so normally some of the asphyxias, (inaudible) some of them will be sucking very well, probably it didn’t affect like their: they are not able to feed very well, we tell them it’s better for them to sometimes it better for them to: the baby won’t cry, so you should get the used to demand, we let them feed at a fixed time so every 3 hours, they express the baby to breast. If the baby sucks a little bit, then they express the rest as cup feeding. So feeding wise, and also things, fever, baby is probably less active, baby is jaundiced, bring the baby back to us. Or baby is breathing fast, we give them things are like danger signs to look out for. Bring them to us, not feeding well, there is fever, baby is less active, they should report back to us, yea. Most too have fixed date to come for review at the consulting room, like every 6 days to come for review in the consulting room. But if you see some of the danger signs, in case there is a danger sign, then you report even prior to the date.

I: Ok, do you feel like usually the mothers understand the special instructions that are given?

P: I think it’s a; you know at times using the some of the English terms, it’s very difficult to find the vocabulary in the local language. So at times, we tell someone something, she’ll look to you like they don’t get who said. They are also: I think that (inaudible) us, so they don’t understand you but they wouldn’t tell you they didn’t understand you, they just nod so you think they understand you. When you ask for a feedback, then you realize it. So I think at times, there is a communication barrier. And in this part of the world, they don’t ask questions, if they don’t understand something, they won’t even ask, they’ll just look at you and nod, and you think everything is ok. But there are times when you have given instructions; they come to the consulting and at times they come like in a couple of weeks. So they come like some even come just for check their weight that they are gaining is significant. But some will tell you oh she never bothers extract, but that’s from: and at times to the nurse is doing mass education. Is not really mass education so at times some people won’t pay attention and then they miss some of this advice we give.

I: Erm so besides what you already just said, if mothers don’t follow the instruction, what is usually the reason why?

P: I think it’s more of communication barrier, that’s the major thing and also the mass communication is not very effective looking at the mothers’ side. At times the mothers are feeding and like they are doing education or counselling. I think somebody wouldn’t pay attention or that so I think it’s more of communication barrier and our mode of communication too. Yea like the mass communication, I think it’s not effective: the mass communication, so I think the one on one I think it’s better. But it’s very difficult having the one on one with every mother that’s quite a challenge.

I: Ok do you think any other cultural barriers besides communication prevent mothers from understanding?

P: Yea at times the mothers think that probably the fathers, some of the mothers, like everything you tell them, I want to wait for my husband to come first. Like the man probably, they feel like everything the man should be informed first. When the father is not around and then they go home, so probably the woman will feel like oh my husband was like (inaudible) so the day for review and the father is not around, they will not come because the husband was not around. The husband wasn’t around she will not bring the child because the husband wasn’t around. Or either she doesn’t have money to bring the child or she’s supposed to seek the man’s permission before she brings the child. But that’s like for the uneducated mothers’ yea that’s the approach like they need the man’s approval before they do: if the father is not around they won’t bring the child.

I: Have you ever discussed one of these cases of babies that survive that you thought they should have died with your supervisor or coworker?

P: oh yea yea yea , so like, I think it’s like we the residents there is always a specialist who have more responsibility than you in anyway so if anything difficulty, they should always discuss such cases with them. O normally almost every critical, look at the child and either you need a specialist or you need a consultant yea. So most of the cases, they are aware of such cases and we seriously informed them, they are aware.

I: and what is usually the outcome of the discussion?

P: the discussion, either it has to be like the management plan, whether there is something you should consider like or, be it more of the management, so there likely like change of antibiotics or BP option or the feeding option so it’s more about the acute care, yea that they offer their input, so that’s supposed to be it yea, it’s more of the management of the acute babies. Or the follow up, continuous visit, yes so they do the: they are reported to the special nurses they still see them.

I: ok have you ever received formal training on how to handle these cases of babies that survive when you thought they would have died?

P: not really not really

I: do you think there should be training on how they handle these kinds of cases?

P: mmm yea, it’s always good to have trainings so yea

I: what kind of training do you think there should be?

P: ok so I think when they come for review there are things to look out for then probably like follow them like the milestone, how they are reaching the milestones. So I think a refresher course like a refresher course for residents but for us yea I think it’s not a bad idea something like a refresher course of the, things to looks out for when the patients come for review.

I: ok, what do you believe is the most important thing to understand in order to handle these kinds of cases?

P: so it looks like in relation to like when they are on admission, or it’s just like after they are discharged and they are coming for follow-up?

I: ok when they are on admission

P: when on admission yes, such cases ok the question again

I: what is the most important thing to understand to handle these cases?

P: I guess like taking the like a multi like you know at times like even with looking after a child when like a social background of the parent, like a social history, what the mother does, like the level of income. But at times when you even prescribe drug, the mothers can’t afford some of the antibiotics. So it based on the mothers’ level of income and some of the like first line and second line antibiotics. So I have like a holistic approach the patient like their social backgrounds helps to know the kind of drugs to prescribe for her. Yea at times too you even have to contact the social welfare to help with each parent should be able buy the drugs for their babies so...

I: ok and so then what do you think is the most important to understand with discharging the baby?

P: discharging the babies, it like kind of the mothers’ level of education to, at times how far this should go or how little they should go. So there are times some of the babies who have syndromes, if you give them too much information may end up killing the child. So you have to very careful with much how much information like those who have syndrome, probably there will a change. A child may be mentally retarded, you may think a measles child probably is not normal, you can have harm the child, so if you look at the level of education of the parent tells you how much information to give them before they go, yea.

I: ok are you familiar with the term near MISS?

P: near MISS, not really

I: ok so near MISS is when you have a baby: well it could be a baby or a mother or a person but a near MISS is when you know for example for a baby, you will see this baby, you really think they are not going to make it but for whatever reason, they do make it. So you nearly missed them

P: ok

I: erm do you think healthcare workers have the same idea of what a near MISS is?

P: no

I: even if they don’t use that word to describe it

P: ok it’s like babies who we think they are not going to make it but they end up making it. So why is it called a near MISS then?

I: mmm

P: why is it called a near, like is it like we nearly missed the diagnosis or?

I: erm it just a way to describe to this particular thing happened to the baby, you know like something they reserve, even they might be on this ward but their chances of making it are really high but even though they are here, but if they are you, you are like I really don’t know if you’re gonna make it, like do you think what doctors think differently between those 2 things?

P: I think they are basically the same yea, like a severe asphyxia baby who like has a very low APGAR scores, is probably not breathing well like on their own, like mostly sometimes babies in this environment a very preterm baby comes with severe distress, like 24 we count it as 28 weeks, early 30 weeks some of the early 30 weeks who are severe distress. Just oxygen and you go like for the baby is going to miss breathing like secondary to respiratory failure. I think we all kind of appreciate babies we kind of normally miss, yea looking at babies so I think we have a fair idea with the kind of babies we think won’t make it, I think it’s obvious, it’s barely the same

I: ok do you think the distinction of near MISS is useful for healthcare workers?

P: the definition you gave, I didn’t understand it right, babies is it like babies that are critically ill and we think they are not going to make it, just use the word near MISS, I don’t think it will make a difference that much, I think it is about getting the explanation, the first that can help the ones who are dying, I don’t think its about naming them. I think it’s about the intervention you can do to help those who are dying, something like that. I don’t think putting a label on them will make a difference.

I: if you knew a baby was classified as having a near MISS event, do you think it will change how mange that baby?

P: yea yea we call them miracle babies like we think the baby won’t make it and they I think yea, I think we have more cot providing we have more follow-up, is the usual crowd you get it. Those kind of babies probably get more, probably they have like treat them more frequently at the clinic, yea.

I: ok what challenges do you think babies who experience near MISS will face as they age?

P: age, I think it’s normally it depends on how bad your asphyxia or condition was, I think it’s more of the neological outcomes, you get it. You have like their speech like the motto, like even when they are growing, they won’t achieve their milestones at the same time as the normal baby. I think more of the neological outcome, like their motto, the asphyxias, we have to access them and all those seriously and see how well they grow.

I: Erm how do you think that healthcare system will respond to their needs?

P: So at least for the motto now they have dichotomy we have physiotherapy for it, instead of like phototherapy, we have like physiotherapy for them. But I think with the speech, am not sure whether the speech therapist is here. I know like sterapor some have like special walking ways and stuffs who know how to help them so basically it’s just physiotherapy they have difficult milestone, like they difficulty in walking and stuffs, just physiotherapy where they have very smart stick when the physiotherapy offer them here. Like some have seizures too, they have anti-seizure medications yea. So I think it’s basically just physio, seizure medication yea, I think Kumasi their specialist is supposed to be around I think one or 2 specialists in Kumasi. But I don’t know how well trained the teachers are supposed to handle, but I think they should be trained handling kids with special needs.

I: ok what do you believe is needed to tackle this issue of babies that: like these cases of babies who survive when it looked like they didn’t?

P: cases like after they survive like <cross talk>

I: yea like making sure they still survive, what is the way to tackling that issue?

P: ok so I think 1, they need their parent to educated on the danger signs, you get it. It gives the child some invasion at home like a preterm likely may have cardiopulmonary conditions, heart rate issues, so educate the parents on what to expect too, you get it. And when they report to the hospital in case they see anything that’s very important. To educate the parents and also like the some of them the child will need to follow-up for a long time so that they don’t go home and never come back again you get it. So we have to really make sure of that and the counselling should be like we have to keep repeating it. I realized that when we tell the parent something ones, it like you didn’t say anything. But even on admission when you tell them anything, they’ll go like you are asking about follow up and review, I think, the more like the more you do your counselling, it’s likely they would understand something yea. It’s likely they will bring the child for review, so parental education, I think that’s the most important thing otherwise they will go home and never come back again. Yea by telling them what to expect, what to expect must be cautiously. Yea because some if they have any negative picture, they may not help the child so you have to be careful. But they should still bring the child for review so I think for review and stuff so I think it depends on the level of education and how much information you give the parents. And them understanding you, you get it, and the child possible will grow up and the parent coming for review.

I: ok do you have any other comments about babies that live even though they look like they won’t, or babies with severe complications that you will like to make that you think will be important for us to understand for the study?

P: ok so what I was saying like here, preterm, severe birth asphyxias, I think it because they are: as far as with the preterm those who die is from the respiratory failure

I: you said with what?

P: respiratory failure

I: oh

P: (inaudible) from preterm, the asphyxia babies too, I think it’s some of them when they come, they are not berthing very well they are not supported so eventually they get tired (inaudible). I think it’s more about the intervention of: you have to it looks just like a more intensive care elsewhere, like so there is nothing really intensive going on here. So I think the level of care will have to speed up like about here like offer more intensive. Although we have specialist just for this ward in general yea, I think we have that properly so we can save more babies, yea. And also educating the public too, the jaundice thing too, mothers will have to examine their babies for the jaundice especially by the time that they come, they already have like encephalopathy. But if come earlier, then the phototherapy may help them. So it wouldn’t get to a state where they need an exchange blood transfusion.

I: Ok well thank you for your time in answering our questions, we hope your answers help us understand more about why babies that seemed as if that they will die live instead. Please let me know if you have any questions?

P: no

I: and if you have questions in the future, I can be reached through Dr. \_\_\_\_\_\_\_, ok, thank you.

END OF INTERVIEW

Type: HCP Interview-CC9012

Date: 13/7/2015

Position: Nurse

I: Ok so thank you for taking the time out of your schedule to meet with me today. As you may know, this project is focused on learning more about the babies who have life threatening complications during and after delivery, but who survive. Your thoughts and opinions about why some babies survive while others die are very important to helping us understand these issues better. As a reminder, I will be recording the interview. This is just so that I have something to help me remember what we talk about. It also means that I won’t need to take a lot of notes, I will just write down what I would like to follow-up on. Just so you know, the recordings will never be played publicly. We will transcribe them and then destroy the tapes. If there is anything that you don’t want to talk about, please let me know. Also, we can stop the interview at any time. Please let me know if you would like to stop. What we talk about will remain confidential. I won’t share the details with patients or others at the hospital. You will not be named in anything that is written about this research. Also just so it is noted on the tape, this is interview CC9012. Uh we would like to learn more about your experiences with babies who are ill and their outcomes. You’ve been working on this NICU for \_\_\_\_\_\_ now. Some of the babies have had severe complications. Some of them, you may have struggled with and they died. Some of them, you may have struggled with and they lived. Some died no matter what you did. Some lived when you thought that they would not have. What would you, what do you think is the difference between those who lived and those who died?

P: That’s the first question, the difference between us, in number or?

I: Like what do you think is the difference between the babies that live and the babies that die, like why do some live and why do some die?

P: (laughs) Mmm, like when they started reading them, no matter what we do some will live and no matter what we do you have to, some will still die, uh huh. The difference, when they come here, I think we follow all the management procedures according to their condition they come here eh with. Being here there has not been an instance that I would say baby died because we did not get eh certain drug that we needed for the baby or not. Even if the parents cannot afford one way or the other we try to get it for them, mhmm. So the difference, that one medically, I can’t attach it to any other thing but to say maybe it’s their fate of that eh baby to live or to die, yeah.

I: Ok, uh can you tell me about your experiences with those babies who live when you thought that they were going to die? What disease or symptoms did these babies have?

P: Ok, uh those that we thought that you were going to live but died but?

I: The ones you thought were going to die but

P: But they lived, ok. Normally uh the experiences (interrupted by person entering room) is is is heartwarming. When at the end of the day you see that ah I thought this baby was going to die but lived, normally cases like em severe HI

I: HI?

P: Hypoxic-ischemic encephalopathy. When normal they came in as eh referral baby so it’s like a lot of time has gone, yeah. Treatment has been delayed, so when you see them you think they are going to ah this baby, this baby will not make it, but you start the protocol for managing the but let’s say you go and you come back the next day or 24 hours has passed, the baby will still be there, you continue the treatment then they live. So when you see that this baby has survived, has been off the oxygen, has been out of the danger zone, it’s so heartwarming, so so it’s so a great feeling uh huh that we are so happy and at times we become attached to those babies yeah. You feel so happy, the work you did, mhmm, so that’s the experience.

I: So what would you like in those cases of babies with the same condition that lived and those that don’t, do you what do you think makes the difference for those babies?

P: Mmm [pause] I really can’t tell what’s what’s in the difference as I said earlier, when they come the protocol is there, you follow it, and the specialist will come in uh huh. As I said, some will come with the severe form of the HI I said, some will just come with just a mild one, yet the mild one will not survive and the severe one will survive. Eh for that condition in particular, when it’s severe they can even bleed. You see those baby bled when you pass NG tube and you will suction so much eh dark fluid and things I’ve seen meaning the baby is bleeding, yet they will survive. And that is the mild one, they will not even em survive. And as I was saying, I’ve been here three years, I will not say because we needed this drug for the baby they did not get it, that was why the baby die. I can find, but I don’t know, it’s so special that even if you have to go to the head of pharmacy to talk to him so that he will get that eh drug for us and later the parent pay or we do them we do them, yeah. So for the reason eh what makes that difference, I can’t tell, I can’t tell.

I: Um is any other special care given after diseases or conditions are resolved?

P: Oh yes. For instance if eh a premature baby comes in, then we manage, the baby survives and eh the baby is being discharged, we intensively educate the caregivers on how to go and continue the care at home. And also eh normally for a premature baby you ask them to come for review in just a week time, eh huh. And also to report to the emergency if there is anything that is bothering them eh huh and the eh well-being of the baby. So we do have that kind of (interrupted by person entering room). Can you pause? (recorder paused)

P: Can I start?

I: Mhmm. You were saying um the premature babies, you tell them to come back after a week.

P: Yea, after a week. And the special care that the parents are to give and even how to feed. For them you also eh advocate, encourage them to continue with the eh exclusive breast feeding. They cannot suck on the breast right but we encourage them to express, make sure the baby they get more of the breast milk than the formula feed and other thing. And for eh another condition like jaundice: Some of the babies with jaundice, normally, they are just (baby crying in background) (recorder paused). This baby, the management, you are discharging the baby, I was making a point like, eh jaundice, after seven days phototherapy is not effective, so normally we switch to the early-morning sunbath, using the UV rays. So maybe we did that time period even discharging that baby, so we asked them to go and continue with that early-morning sunbath and also continue with the breast feeding because that will also help. It helps clear the sclera of the yellowish and the skin and other things, yes. So for eh special care it’s this. It’s almost every discharge we do educate them on a special way to manage them, if a baby has a deformity like a cleft lip or palate, you have to educating them, letting them practice on how they are going to feed the baby at home and things like that. We do also encourage them to continue with those special care and maybe the medication giving them and other things yes.

I: Ok, are mothers typically given special instructions, for also like you said, the special instructions for caring for babies that lived when you thought they were going to die?

P: Yes, yeah.

I: So is there anything else um that you haven’t mentioned that is specifically told to them?

P: (pause) They are plenty. And I don’t think you can go on with every single condition uh huh. So it’s like I generalized it and brought out some of the commonest ones that we do encounter here. So we do, we do. We do educate them on some special care and other things. Normally with the preterm babies. Yeah, in that part of the ward they do bath the babies so much, you bath them in the morning then in evening. If it’s a preterm you ask not to do that, because we are trying to keep the baby warm. So you the more you expose the baby to bath, the more the baby will get cold. For such a baby you will you will you try to, I should say that because they do not want you to take the baby home, the baby becomes hypothermic, you write the baby and things might go wrong. So normally we encourage them to do [inaudible-10:08] that is just when the baby will bathe with the sponge and the [inaudible-10:12] yeah. That’s the special care and also educate them on kangaroo mother care. Yeah that one every preterm baby, even at term low birth weight baby, term low birth weight, we encourage them to do kangaroo mother care to keep warm and put the bonding between them.

I: Do you feel like mothers usually understand all of the instructions that are given?

P: No, no I don’t because those that come see, um most of them, most of them (pause) educational level is basic. Not even high school. So they do not understand or that’s why after educating, after knowing the person’s educational background, when you educate the person you make sure the person like um repeat whatever you tell the person. For instance, if it is feeding with a cleft palate you should like this. If I educate you, I will make sure you do it for me to see and not once. If you are preparing to discharge the baby, you may like to start about three days earlier. You two will be practicing feeding the baby and when you see that they are competent, before you are discharging. And that same with the breast feeding cause when you even sometimes have to attach the babies to breasts, they are not too conversant with it. So yeah from day one when the mother comes we start eh educating them we have we also have eh posters, pictures, things that we like we tell them look how this woman is eh holding the baby as position the baby for feeding and things like that. It’s just in front of them where they are sitting. The pictures are just there. So as you educate them, you also encourage them to look on those pictures to eh learn, yeah. So we we we do that, we do that but so you see we don’t all have the same IQ (laughs) [inaudible-12:16]. Some people, no matter how much you put the words into their head they can never write their name, yeah. So for such a person like that you may get the husband to support or the any other person from the family to support. Because after all, all of them can not be eh, sorry to say, dumb, eh huh, yeah. So we do get somebody to come and you educate that person too. Especially the case of teenage pregnancies, those 15 years, 16 things like we know that they are unable. They are, they cannot take the care of those baby, that’s the fact. So that one, even before we discharge we make sure your mother will come or your grandmother, whoever is like old and able to take care of the baby comes, we educate both of you before we discharge those babies to their mothers, yeah.

I: Ok, so besides the reasons you know them not understanding, when mothers don’t follow the directions, what is usually the reason why?

P: It’s because they don’t understand and refuse to ask questions because at the end of the day after educating them, you ask them, “You understand everything? Is there any question?” They will say no. One funny thing is when you tell you are going to discharge they are so discharge them they are so in a rush that you can see when educating someone the person is not listening but when you ask “Are you okay with this?” she will say “Yes.” “Any question?” “No.” And so you ask the person to repeat whatever you said or to eh demonstrate to you what you did. Then you find out that the person didn’t get whatever you taught her uh huh. So, that is it, those kind of mothers, they will not voice their thought. As I said you will ask them question for them to let you know whether they understood it or not uh huh.

I: Do you feel like there’s any cultural barriers to the mothers following instructions?

P: Yes, there is. It’s still existing here in our part of the world because earlier question you asked eh I said yes I understood you make them demonstrate they will do it perfectly, yet they will go home and do a different thing because there is a grandmother somewhere that says, “No, you, your time, I did this for you and it worked so let me do the same thing.” Example is in the case of their cord, how you take care of the cord. Some of the babies, they by the time they are discharged, the cord is still on, it’s not fallen off. So we have to educate them, even here because of that temptation of eh them using some form of herbs and other things to dress the cord to get it infected we tell them to send it to the clinic near them to be dressed, to be dressed. Yet when they go home, a mother, a grandmother will say, “No, you, your term. You’re my best. I did this, I used this herb and it worked so why are you telling me to go to the hospital for them to use this contemporary drugs and other things.” So yeah we still have em cultural barriers to home care, let me say home care, we still have cultural barriers to that. And most times they will go and they will come back with their cord for instance, they will come back and the cord is infected, we have to readmit the baby, yeah and treat. So cultural barriers to management is still there, still exist.

I: Like what do you feel can be done to prevent those kind of things with that kind of cultural barrier?

P: Education, education, education and it has been done. It is being done, I will not say it isn’t. From the day they get pregnant they start the antenatal clinic, they will tell them how to take care of the baby, how to dress the cord. Because they say the cord, some ?time turned back? , it was killing the babies, it will get infected and by the time they come here, the baby will get very high temperature that they can even convulse and other thing. So I would say the health, the Ministry of Health is so concerned about those issue. So that that is why they even asked them to stop dressing the cord in the house and bring them to the hospital for the nurses to attend to those cords. Yet people are refusing to accept that form of education (talking in background). (pause) Yeah people are still refusing to accept that form of education and eh It all boils down to that eh cultural barrier. ‘Cause there are some people, no matter what you do. It’s like you tell someone this is white, the person will say I see red, so no matter how much you educate, no matter the evidence you show the person, the person will still say I see red, this is not white. So dress the cord in this but the person will still say no, I use this one. At times it’s funny because when you are educating them, they are in their minds they they are laughing at you cause you don’t know what you are saying. I mean when I go home I’m going to do this and do that. You advocate for exclusive breast feeding that they should stop the artificial feeds uh huh because here the form of preparation can attract so much infection to the baby and other things. Yet somebody and even with artificial feeds economically, it is very expensive here. Yet a person who is very low at the cost of living, living standard, somebody who is very low will still go home and choose to feed the baby artificially. So instead of the proportion or the ratio for mixing the feed, they will not go by it. Take 13 mils of water with one scoop of the feed. They will go for 100 mils of water with one scoop of the feed. Yet their breast is at their chest lactating, so they want to go for that. So education has been done, I don’t think it, some don’t take it.

I: Ok, have you ever discussed one of these cases of babies that survived when you thought they would’ve died with your supervisor or a co-worker?

P: Oh yeah, so many times we do. We do discuss them. ‘Cause in our department almost everyday we have some form of clinical meeting. We have a day that we discuss mortalities, yes. We have a day like a clinical day we pick a topic we discuss it un huh and other things, so we do. When a case like that surface, when we come across that we are able to manage then the baby stays. We do talk about it.

I: Um so if members of your team discuss these cases, what is usually the outcome of the discussion?

P: For instance, if (pause) the baby, we think the baby will die but through the management maybe they didn’t die. We might have done in the management, it’s not always static, it’s dynamic. Maybe you are giving oxygen alright but this time, I give the oxygen uh through face mask, I didn’t use nasal prongs and I saw that the face mask helped the baby and the baby lived. So in that case, em is is is is em a point that we need to note that next time a baby comes in with such a condition and we are trying the normal protocol but it is not working. It’s a good thing you have to visit it or revisit it and pick it and use it yeah. So apart from when outcome everybody is so happy, if, I don’t know, at times you do clap.

I: Mhmm.

P: You do kind of if this child’s been on the ward because we are all so amazed, so happy to see that that baby is thriving and is doing well un huh. So apart from that feeling we do also encourage ourselves to put into practice whatever new that we introduce it help the baby to live.

I: Ok, have you ever received formal training on how to handle these cases of babies that survive when they look like they would’ve died?

P: I mean, training. I will say no. I’m a general nurse but I’m working in a neonatal intensive care unit. I’ve not received training on that. Training I I receive is in service. When I started the job un huh then I’ve been going for workshop and at time the ward or the unit will organize some of eh the service training for us, yeah. So the only training I have gotten is on the job, but not from any educational institution.

I: Ok, um do you think there should be more training on how to handle these kinds of cases?

P: Oh I do, why not? If you want to increase their survival rates and we are working there, I’m working there. So I think we need to be educated more on these cases and their management. Every single person on that unit has to have a formal knowledge in the management of these cases on the ward.

I: And like what type of training do you think needs to be added?

P: Specifically or are you talking about theory or practical or according to condition?

I: Um, either or any of those. (person comes into room, background noise)

P: Well then I would say we need all sorts of training.

I: Mhmm.

P: Theoretical, practical, and also when it comes to individual condition that comes on the ward. We do need training from time to time. For instance, in the issue of [inaudible-24:14] of the baby, it’s it’s on our unit it’s a procedure that I think at least every year, we need to be trained uh yeah. ‘Cause we do get new ones and new things do also come as time goes on. Yeah, so we do need training in all forms.

I: What do you believe is the most important thing to understand in order to handle these kinds of cases?

P: The most important thing in handling these kinds of cases. When you make it general like this, I don’t. Let me answer generally. Considering all the cases that come the the prematurity, the jaundice, the asphyxias, um… the deformities. I think the first time care is very important in first year. Whoever is there to admit the baby into the ward, whatever care they get really counts. Because if their starting point is good we could save the baby who we think will die. Yeah, if the starting point is good, yeah. So the em initial stages, the very first time the baby comes to the ward, the care that we give I think is very very important, yes. No matter the condition, I think it is very important. For instance, if if a baby comes severely asphyxiated and we check the SpO2 and it’s low, below 90…some of the babies have saturation could be below, as I said below 90, 80, something like that but the rhythm of their breath will be fine, will be respiring very fine. But if we the physical display we say this baby is okay, I will not give oxygen. Then we check the oxygen saturation you see that its low, yeah. So if you give this baby oxygen at that time it will help with the prognosis, let me say that. Because you might have left the baby there without the oxygen inwardly something is wrong, something is happening that the baby needs yeah management, yes. So if the baby comes like that then uh you are lucky or fortunate to have been pulse oximeter to do all the necessary assessment and you are tend to the baby and give the baby oxygen, it will help. Yeah so the initial management is very good with uh, let’s say, um…just let me say a day old jaundice. The baby comes, you see that the baby is yellowish but the baby is not ill. You see that the color is yellowish even the sclera, the eye, is not that yellow but you can feel from the skin that there are some stage of yellowish coloration discoloration in there. Such a baby the baby feeds well too, the baby is feeding well. If you are able to get breast milk for that baby, to feed on instead of the formula, it will help clear the that yellow discoloration faster, yeah. Cause that you’ve even given phototherapy because at times after ruling out maybe the possible cause of the jaundice, oh it’s just a tint of jaundice. Because at times some of the babies they have not been feed well. Their mothers are not lactating yet, so they are not getting anything uh huh. But when you are able to get the mothers, nurses they will start it for them, suppose they are able to feed well it does work well, yeah. So initial management is important and in the case of medication, drugs un huh that even if a baby comes to the baby is bleeding from maybe a cannulas puncture site. You normally use vitamin K. We read the history or you took the history from the parent, they have not been given vitamin K. We need vitamin K for this baby, if you get the vitamin K for the baby it will help the baby but if you not get, no matter how much you put pressure on that bleeding site, the baby is still prone to it because whenever you prick another end it will still continue yeah. So when the initial all things are in the right way together, initial management done well because all will to help with the prognosis of the baby.

I: Are you familiar with the term near miss?

P: Um, yes.

I: Ok, can you tell me what it means to you?

P: Near miss, like as um for my what I understand it’s like nearly we missed that baby.

I: Mhmm.

P: Yeah, but something went on well somewhere so we could save that life.

I: Yes, that’s right. Uh do you think healthcare workers all have the same idea of what a near miss is?

P: I wouldn’t say yes cause I’ve not questioned everybody

I: Mhmm.

P: on that. Yeah so I don’t say yes.

I: Is it a distinction, like knowing a baby had a near miss versus not, is it a distinction you think is useful as a healthcare worker?

P: Hmm…yes…because at times when I came to the ward this afternoon they were just telling me that a baby on oxygen that we should make sure the oxygen doesn’t go go off. Because such a baby, if the oxygen goes off we may lose the baby un huh. So um the decision as of this baby you know as it is, it’s a near miss baby but there was um in the management we were able to get all that we need so we were able to save the baby with the same em oxygen issue. The baby comes in, even the baby needs oxygen and oxygen is available and we get it for the baby, the baby is saved. You know you need oxygen for this baby or else the baby will not survive, since there is no oxygen.

I: Mhmm.

P: So all you can resort to is to ambu bag. How long can you stand on the baby to ambu bag? So the decision is if you have all the requisites, the needed items that we need for the job, then I think we could save some of these near miss babies.

I: So, if you knew a baby was classified as having a near miss do you think it would change how you managed that baby?

P: We are in a critical care unit, yet some conditions are more critical than others. So if a baby, I see this baby to be in the near miss category, yeah their care will be different from a stable baby. It may this baby has to have continuous monitoring… yes no matter what, if you have to put the baby on cardiac monitors so that because one issue is here normally ehm the patient’s staff strength is weak um two staffs or three could be on the ward managing about 20 babies or 15 babies, yeah. So we cannot just give one person to take care of maybe one near miss you cannot do that.

I: Mhmm.

P: So what could help is to put the baby on em those cardiac monitors if they are available because for that one if they see any change it will pick so you just rush to that place uh huh. And even if you do not have that one, what you can do is your frequent monitoring. You can make it eh every 15 minutes or half hourly or things like that. Make sure you go to that person that baby to see what is going on. So definitely caring for a near miss baby is going to be different from even a ill baby ‘cause that one is critically ill.

I: Ok… um what challenges do you think that babies who experienced a near miss will face as they age?

P: (pause) Ehm this severe HI that I mentioned earlier, if the baby survived sometimes they will have some sort of growth retardation and even their developmental stages normally delays. Eh even that same thing also goes for a complicated jaundice that and the baby developed kernicterus. They have that delayed in developing and can even go on to affect even their IQs and other things. So this kind of baby normally we educate the mothers the possible outcomes.

I: Ok, what do you think is needed to make sure these babies live long term after their near miss?

P: After the near miss because after that they will be discharged home and because we know that they were critically ill but they survived, we will make sure they are reviewed, they are referenced, their are follow-up visit to the hospital it’s in short periods, but normal one week, seven days they will visit [non-critically ill babies come once a week]. But when they are being discharged for us as health workers we do educate them to come regularly for follow-up visit. But the…em most of the work is with the parents, the caregivers, when they take them home, yeah. Most of the work is them. So when they sit up when they follow our um education and our guideline that we give to them to take home and continue with the care. When they go to follow that, I think it will go a long way to help in increasing their survival rate yes. That’s what I say yeah. The home care, it’s the home care. Because normally from our place, NICU, when they come for ?(immunizations)? when they they are that one is 28 days old, 28 days due they come for ?doses? and they will be on the pediatric ward, yea. And at times we do see some of them. This is a near miss, we do we worked so hard on this baby, the baby survived, we are so happy. We educated the mother what to do and you come and see them on the pediatric ward. Refusing to do what is supposed to have done. I experienced one and that one, I took the baby in on arrival, I took the baby in. Oh the baby stayed on the ward more than a month. With the start, the mother was expressing and feeding the baby so the baby could suck from the breast. We dey start her educated her to continue with the breast feeding also expressing for the baby. This lady went home and came back to the pediatric ward. I happened to see her there and I asked her what happened. Instead of the breast milk she was mashing kenkey, yeah, for the baby. So you see likely she was discharged from the pediatric ward I have not seen her so don’t know what came out. So that is how some of the mothers can do. So in our part of the world it’s the home care, it’s the home care that can go a long way to help with the survival rate of the near miss babies.

I: Um…how do you think the healthcare system is prepared to respond to any needs babies that had a near miss may have in the future as they get older?

P: How much we are prepared?

I: Mhmm.

P: (laughs) You know it, we are we are in a developing part of the world. We are not developed yet. So we don’t have 100% system here to take care of those things.

I: Mhmm.

P: But as it stands now, well I could give 60 to 70 percent yeah and my mates I can’t talk for. For a year now we have gotten some of the needed equipment mhmm that we are using to help out. We use them, we’ve gotten some eh incubators, ventilators, cardiac monitors that are needed for this kind of critical cases yes. But as it is we are a developing world, maintenance is very poor so they do break down and they are not fixed and other things uh huh. So I would give it that as it stands now that we are doing the interview, I would give it 60-70 percent capability of the healthcare system to support the near miss babies who survive.

I: Ok, um so do you have any other comments about near miss babies and how things are that you think are important for us to understand for this study?

P: (long pause) Yeah, ehm study is about you want to increase their survival rate yeah. Strengthening the healthcare system, we need to strengthen it. Because when they come in, then your assessment reveals the needed care and they are all available. I think if now we are saving 30 percent we can double it if the healthcare system is being strengthened yes. So for the study, as researchers, you need to know that we need to strengthen our healthcare system.

I: Mhmm.

P: Then also this point the education of the caregivers. We educate them, we educate them. Even some of this management has been advertised on the television and the radio. But some of them are so stubborn to go with it. But still we don’t have to give up, we need to educate them well too. The caregivers that take those babies home un huh. But they continue with the appropriate care. Then in strengthen the healthcare system, which I think the staff on the ward, the working staff, they too need to be em trained. They needed to be supported in pursuing their education in that field. That’s what I think.

I: Ok, when you say strengthen the healthcare system what what parts do you mean need to be strengthened?

P: The human resource. Then um logistic like material resources, these vary too. They need to be strengthened. As I told you earlier, we could have just two nurses on the ward caring for 15 to 20 babies and of that you can have a dozen of babies are critically ill. How much can these two do for them? But let’s say their number was a bit high, let’s say they doubled that time will also be doubled yeah so the human resource need to be strengthened. And you strengthen them you need to be training them too, educating them on newer techniques and skills. That they don’t stay there with the old manage because things do change. As you are carrying out your researches, you come up with new recommendations and suggestions. So I think when such em a review comes out they need to know, they need to be informed. Yeah and normally apart from maybe it being at the times on the regional division on the major. That it comes in the form of workshops and other things. So encouraging the staff also to partake in those em workshops is important. Yeah some they need to pay for things but the others, I think the management of the institution can sponsor something in those kind of training and other things. Then in the issue of the ?(equipment body)? for the em management of those babies, if everything we need is there then I think at the end of day we will not cry out that if this had been there the baby wouldn’t have died. Although you know that this is a near miss but yet something was lucky. Maybe I wasn’t getting em oxygen, enough oxygen for the baby because at times the cylinders on the ward they do get finished. And you know that this baby has to continue on oxygen but the cylinder is gone. Maybe when you are taking up you knew it was getting finished, you make the call to the department to fill your cylinder for you, they have not come, what all can you do? So if these supplies come in at all times I think it will help. I need em pulse oximeter to know the oxygen saturation of this baby, it is there, I don’t have any problem. I check it, I know what it is going on uh huh. I need nasal prongs to give oxygen, it is there. I need facial mask. One problem we have is facing on our unit now, when you have to give official masks administration of oxygen at times its difficult we have to improvise. You will get the mask alright, it’s not enough too but you may happen to them. If you have two babies or three on the shared mask, it mean the fourth one will not get it because we have finished. And even those on it you have to improvise you have to uh make your connector. So you use some syringe, we cut it to make the connector for the baby. And let’s say, by the time I go for a surgical blade to cut the syringe and connect it and plaster it and connect it to the hose, it will take time. But if every ?(cassette)? was there I will just what unwrap it and pick it and connect it for the baby and time would have been saved. A condition of the baby too would have improved within that lost time. So you see so if all those things are there it will help us. A baby comes in very cold, a baby needs warmth. If I have a dense warmer and put the baby under it, in less than five minutes the baby will start responding. Very cold baby that they even come and you say they are blue. You will think its lack of oxygen or inadequate ventilation, you warm the baby and the baby becomes pink and you see that it wasn’t about oxygen. Cause if there are needed items are there it will help, it will.

I: Ok, well again thank you for your time and answering our questions. We hope your answers will help us understand more about why babies that seemed as though they would’ve died live instead. Uh please let me know if you have any questions.

P: You are welcome. (laughs)

I: (laughs) Thank you.

P: You’re welcome but not a question per say, but I think at the end of the day the outcome of this research will help to improve the system we are enduring now. Yeah because you want it to want it to. Because as a nurse it’s so exciting, heartwarming, a good feeling, when after your shift you think you were able to save a life. Even though you may go and come to see the baby dead. But when the baby came on your shift, you were able to stabilize the condition. You just smile in your head as you go home, yeah. So I think as this eh research being carried out, at the end of the day, the outcome will come and help us. It will not just be one of those research for em academic purposes to get the eh what is it ? The degree, the title and that is all. I hope it will come and help.

I: Yeah, me too. Um if you need to reach me I can be reached through \_\_\_\_\_\_ um so she’ll have my contact information. You can also ask her any questions if you have any.

P: Alright, thank you.

I: Thank you.

END OF INTERVIEW

Type: HCP Interview-CC9013

Date: 15-7-15

Position: Nurse

I: Ok, so thank you for taking the time out of your schedule to meet with me today. As you may know, this project is focused on learning more about the babies who have life threatening complications during and after delivery, but who survive. Your thoughts and opinions about why some babies survive while others die are very important to helping us understand these issues better. As a reminder, I will be recording this interview. This is just so that I have something to help me remember what we talk about. It also means that I won’t need to take a lot of notes, I will just write down what I would like to follow-up on. Just so you know, the recordings will never be played publicly. We will transcribe them and then destroy the tapes. If there is anything that you don’t want to talk about, please let me know. Also, we can stop the interview at any time. Please let me know if you would like to stop. What we talk about will remain confidential. I won’t share the details with patients or others at the hospital. You will not be named in anything that is written about this research. Also just so it is noted on the tape, this is interview CC9013. We would like to learn more about your experiences with babies who are ill and their outcomes. You’ve been working on the NICU for \_\_\_\_\_\_ now and some of the babies have had severe complications. Some of them, you may have struggled with and they died. Some of them, you may have struggled with and they lived. Some died no matter what you did. Some lived when you thought that they would not have. What do you think was the difference between those who lived and those who died?

P: In what terms?

I: Like just in general from what you’ve seen. What do you think is the difference between the babies who live and the babies who die?

P: Hmm babies who live maybe we receive them earlier and the attention to giving them was prompt. Some of them and and most of the those who survive are from this hospital

I: Mhmm.

P: And the referrals from the other peripheries, yeah. Sometimes they will come, they won’t do anything. They come in the worst state. So we try and uh and then they die. And those who may die in this hospital too, it’s that the mother was referred to come and deliver here. That time they might have gone through prolonged labor.

I: Mhmm.

P: And baby come in with severe distress. So we try and they don’t survive. Some of them too extreme preterm.

I: Mhmm.

P: Mhmm, those ones who will be here and we try and then they die. Others with other complications, severe maybe neonatal sepsis, cord sepsis, bleeding. They will come in the worst state yeah. So we try and sometimes they won’t be able to make it mhmm.

I: Um, can you tell me more about your experiences with those babies who lived when you thought that they were going to die? What diseases or conditions did these babies have?

P: Oh yeah, ehm one experience is uh on eh the neonatal asphyxia, birth asphyxia. Yeah, we received see the baby with Apgar 1-2 from delivery suite, a teenage mother, according to them, pushing was a problem. So they tried this lady l and eventually they went for CS. Can you imagine this? There in prolonged em labor and later they enter that from CS. Baby came in with severe birth asphyxia, not breathing anything but we tried and they survived. I have one baby on my phone who survived that, that I was very happy to see this baby mmhmm. So I visited them, baby is doing well so I have become very happy when I see that.

I: Mhmm and so like in the case of this baby surviving, why do you think it survived versus other babies with birth asphyxia that don’t make it?

P: Hmm mhmm, in fact, individual difference. I received that baby, I made sure the doctor is available and the line with IV access given. I started my treatment in IV infusion, given. So treatment was promptly given.

I: Mhmm.

P: But in case they meet others, doctors won’t be available, they have to be called. The doctor on duty might be in emergency doing something, maybe here. Cause when they are prolonged the one doctor on duty taking care of people, babies at the emergency pediatric ward and the NICU. So when it’s not the NICU at that time, nurses have to call them, before they will come and give get uh IV access, give treatment, all after delaying. So when we delay a little then things become worse uh huh. So it I think it’s the delay that makes the babies maybe died. That’s the difference. But when the doctors are around, nurses are arrive and available then it start ?(fresh)? then you get the babies alive.

I: Ok, is any other special care given after the diseases or conditions are resolved?

P: Hmm when when they survive from the complication. Oh for us, our duty is to just the normal care after that we educate the parents to go and continue. And if any uh in case of any special care we will refer to the physiotherapy uh huh so they continue the care. But as the the NICU nurses, we don’t do any extra apart from our bathing and then feeding and medication, any any special care then you refer to the physiotherapist.

I: Mkay. So are mothers typically given special instructions for caring for babies that lived when you thought they were going to die?

P: Yes, yes, yes. We give them very well. We make sure educate them, teach them. Right from day of admission. Then we do the care with them, teach them right from admission til discharge. So when they go so some of them may be coming for eh review a week then we make we give them three days and so every three days when we see they are doing well then we give the weekly reviews uh huh. So they come with the baby and then we see and they go back home. But was the (mumbles) something we do.

I: Mhmm, and do you feel like the mothers usually understand the instructions?

P: Oh yeah, they do, they do. We give time to ask questions. Just like the uh preterms babies we can do kangaroo mother care for them. They will be here they will practice, teach them how to tie. Their husbands who will come, we teach them their other their mother, that is the grandmother of the babies will be here, we teach all of them then we let them do for us to see. And they will do it for some time before they they are discharged mhmm. And they go, we educate them to do it, continue.

I: Mhmm, ok. So when if moms ever don’t follow the instructions, what is usually the reason why?

P: Hmm, over here when you teach them they do. But when they go home and they don’t do. We don’t see. We won’t be able to see whether they do it or not. Well if they don’t do maybe it maybe pressure. They are not getting support yeah. Maybe they are single parent. Thinkin’ about what to eat, what to give to the baby. The mother hadn’t eaten and telling her to go and do maybe kangaroo she might not. Other problems there and there are other siblings crying for food and other things. Maybe some of the reasons that I can.

I: Ok, do you feel like there’s any cultural barriers (phone alarm) to moms understanding instructions?

P: Mm oh ok, cultural barrier. I don’t think, I don’t think, uh huh I don’t think.

I: Ok, have you ever discussed one of these cases of babies that survived when you thought they would’ve died with your supervisor or a coworker?

P: Oh yes, we do. We do morning meetings here. We discuss them every time, almost every week we do it.

I: Mhmm, and so what is usually the reason you discuss them?

P: Cause sometimes we about the way they die.

I: Mhmm.

P: And how even the referrals, how they come in mhmm. We receive eh preterm baby very cold, hypothermic. They don’t wear them dresses, they don’t cover them well, at least taking kangaroo mother care. If doing transfer, they won’t do. Even coming with an ambulance, they won’t, they pick a taxi and the relative will just bring in the baby in a wet eh cloth. And while they are damp and soiled they’ve come with ambulance, and oxygen. I think it’s that [inaudible-9:36] that they will come no oxygen. And so when we discuss those things then we give them feedback to the parent. Sometimes our delivery suite uh huh. We discuss then we will invite them or sometime we go there and then tell them our problems. As to what to do when they are transporting the babies.

I: Mhmm ok. So usually the outcome of this discussion is new ways to fix problems, is there any other outcomes from these discussions?

P: Hmmm and also the the hospital write report and do deliver and write on each baby so that our people our eh bosses read it every day. So that we discuss on how to go about it how to communicate to to the um the district, other district and referral point and how to also em to what to do here. In case where we are machine problems when we get it, if they are to give us something to work with when they also eh take part in that and give us whatever we need for our work.

I: Mhmm, ok. Have you ever received formal training on how to handle these cases of babies that survive when you thought they would’ve died?

P: Yes, I have. But others haven’t.

I: So what, like what formal training?

P: Oh! In fact there was a training on from Jhpiego we did neonatal resuscitation. And they brought their equipment, they taught us how to do it. And how to promptly take care of the baby within a minute, the golden hour. And then others too came, I think I sent two of my nurses to also go and learn, yeah. And then we do in-service training over here. Sometimes we invite somebody from somewhere and then come and train us on this programs of the baby. Hand-washing and decontamination. Come and teach us they teach us sometimes.

I: Ok uh do you think there should be more training on how to handle [cross talk]?

P: Oh yeah. For that one there should we need more training but new staff coming everyday. So if we everyday we get new staff they are also need to be trained yeah. We need it almost everyday and more.

I: Are there other trainings that you feel like the staff needs?

P: Mhmm, natal [/neonatal/] resuscitation and with house officers some are gone, others have just come.

I: Mhmm

P: The nurses some have just come in. So the neonatal resuscitation and basic life support mhmm, basic life supporter. I think the basic things if we know how to do it, it can help us. So the new ones need to be taught. And then how to care for babies. We are feeding terms everything. We do they need to be trained. See the general we do it too but the specialty. Those who haven’t attended the school wont know. Even those at the special schools, we don’t even normally train us in neonate, things about neonate. It is the pediatric nurses, if you haven’t learned pediatric nursing. Some people here have but yet when they come they can’t. But when you get constant ?(at risk)? training I think it will help us in our work.

I: Mhmm ok. What do believe is the most important thing to understand in order to handle these cases of babies that looked like they were gonna die but they make it?

P: Hmm…hmm I think I think. Uh the question again.

I: Like whats the most important thing to understand generally about these cases?

P: About those who are dying or who survive?

I: The ones that looked like they were gonna die but survived. Like how [crosstalk]

P: Yeah sometimes you don’t know you can you do your best and they survive. You think they will go but you you will be there and then they they start making it. But the fact I can’t really tell, but I think it’s hard-working and then team working mhmm. ‘Cause everybody does his or her best able to get up, we give our treatment as ordered correctly, dry dosage is given. I think, and then promptly, cause people will be skipping. If you don’t get committed workers, they will be skipping treatment even feeding. Say feed 5 mils [/mL/] they will feed 10 mils, babies will aspirate. NG tube they will be feed by mouth and they will be aspirating. But if you get people who are committed I think then everything will be done (mumbles off) and things will be fine.

I: What do you think is the most important things for moms to understand when their being discharged with their baby that almost died but made it?

P: Mhmm in fact we tell them to handle them with care. Sometimes it’s not, we believe in God so we tell them maybe it is God’s own will. The baby has been saved by God not we the human, we say that they should take good care of this baby. I mean common hand washing, common hand washing. You should be washing their hands very well. Because they way they will suffer with this baby. They shouldn’t be putting herbs giving and treating the babies with herbs. They shouldn’t I mean they should come for reviews. I mean we warn them strictly but that baby that baby handle them very well. Feeding well, if they don’t understand anything they should come so where they’re almost gone and they survive they should make sure. Mmm cord dressing, they should bring it to the hospital, they shouldn’t even do it in the house. If um you see any change of condition they just bring the baby, they shouldn’t delay in the house. So that we don’t bring another problem.

I: Are you familiar with the term near miss?

P: Near miss, yes, near miss, will you explain it further?

I: (laughs) Uh well so a near miss is what we’ve been talking about so like when a baby looks like they weren’t gonna make it but for some reason they do so you nearly miss them but they survive. Do you think near miss is a distinction that is useful to you as a healthcare worker?

P: Mhmm, sometimes…sometimes, cause as I said there was this uh baby with Apgar 1 and 2 there wasn’t any way for me as a human being, I could say this baby wouldn’t survive with this Apgars. But like the baby escaped death and it like almost the same as a near miss yeah. But we started to seeing improvement, started breathing well. And it’s not the only one, this not the only one. We’ve been getting them, they will come and the worst state as if they were going to die but they will be there. Especially that the severe neonatal asphyxias, then they they they they survive. So mhmm.

I: Mhmm, ok. So if you knew a baby was classified as having a near miss event, do you think it would change how you managed that baby?

P: Mmm, yes. Because that one need special care, need attention. So over there what we do is it’s like if I’m on duty I make sure, somebody, you assign somebody to take care. If suctioning, they suck; if feeding, we feed; if medication, we give. We give everything correctly and according to time, mhmm. So we give special care for these baby but the babies will be there plenty. But if we don’t give attention to this one, it might go. So always we assign somebody, a nurse, if possible. Do the in charge, you take care of that baby and so that it gets…

I: Ok, what challenges do you think babies who experienced a near miss will face as they age?

P: Mmm, some of them if they’re birth asphyxia might not be able to um their IQ might not develop well.

I: Mhmm.

P: If severe neonatal jaundice, might delay in their eh motor, mhmm walking, sitting mmm. And there will be some like form of autisms mhmm in them. That is what I’ve been seeing in those babies.

I: Um do you feel like the healthcare system is prepared to respond to the needs of those babies as they age?

P: Hmm for that one they are I can’t tell. I don’t think the health system is ready. But we apart from referring to the physiotherapist that’s it’s best that but we eh might not be able to do eh all. They will try and then discharge, they go home with just complications so there. So the mothers become so desperate and even yeah almost curse God by giving them, for giving them such children. They become depressed and uh huh. So the health system I don’t think they are ready, they’re not ready. The government should should should come in mmm.

I: So what do you feel is missing from the healthcare system that makes them not ready?

P: Mmm they will tell you, in fact we we after the curative aspect, the rehabilitation aspect and eh eh uh in the system is poor. We don’t have the facilities for the rehabilitation, yeah. You see if if if even if the adults [inaudible-20:28] there is that facilities are not enough here. Like somebodies IQ they have to the have to be maybe getting reeducation, special eh schools. We have it but it’s not enough uh huh. So I don’t think that that that institution is ready to take care uh huh of that. So they leave you in the society just to be there like that. But if your parents are not well-to-do you will be there.

I: Mhmm ok. So you mentioned like sometimes this causes depressions in the mom. Um is there some way that um you are able to catch that depression that the mothers have and treat them?

P: Mhmm, uh sometimes. Because when they come, we expect the weigh to be increased, they come, a month and the weight reduced or the same.

I: For the baby or the mom?

P: For the baby, for the baby. You see the mother, the mother you ask. When you ask, mmm you see I mean their expression from their faces. And some will tell you, this is my problem. And some of them they come, they are readmitted. We have a lot of them they have admitted again in pediatric ward. Because when they go they they don’t really do what of most of what we tell them.

I: Ok, uhh so what happens when you realize that a mom has depression from whatever is going on with their baby?

P: Mmm sometimes we involve their other relatives. Their husband, their mother, and the others we involve them. Then we counsel them, talk to them, whatever the problem is coming from. And then they also assist (phone alarm), mhmm.

I: Ok, um what do you believe is needed to make sure these babies that have experienced a near miss live long term?

P: Mmmm…Can you explain it further so I will get it?

I: What do you think is needed either in the healthcare system or on your ward to make sure like once these babies survive their near miss experience, what do you think is need to make sure they survive after that?

P: Oh, hmm I think the healthcare system you have to get maybe counseling unit. This counseling unit come in this hospital so that we refer. I think if now we can do some up there. This counseling unit, this hospital has just gotten some. And pastors are there so that after here we refer them. So the mothers we will take care of them. And because most of them survive long, they are older they come here to show them to us. There was one baby was from \_\_\_\_\_\_, a preterm, he was always going into apneic attacks, mother would be crying. Now baby, the boy is at school, class 4. So they are there and some of them we need as I said, we needed counseling unit but we have one here we have to refer them. And also follow them up, encourage them. By the time when somebody come from (names city-24:18) , the western region, someone will come from \_\_\_\_\_\_, far far transportation. The hospital may not give me car to go there, even ?(G and T)? money for transportation because we have to do follow up, mhmm. So I can’t do that so the public health nurses have to come in. And that is what we are not doing. So that like we refer them to the public health nurses around then they continue with them and bring us feedback. So what we do here is we take their numbers, phone numbers, they take ours. When they go they have problem they call after we discharge they call. Then we also call often and then we communicate. So when there are problem we just (phone rings) there was one baby from (answers phone, recording paused).

I: [restart tape 25:14] Ok um ok I don’t know what you were last saying but we will just go on to the next question. So you said that there’s a counseling unit here now. How is that different from when the moms come for the reviews?

P: That one is different from like we the pediatric unit should have gotten ours. That one is for the whole hospital. We when they come I start educating when they they are being discharged I educate them but we should’ve gotten our own. Apart from the education, we just counsel them and their conditions as to even before when they come, you start the counseling, the condition you explain to them, the outcome, prognosis are gotten. If they know then we counsel the [inaudible 26:05] how they can cope, then we help them. But this is the case. We don’t have and because of the pressure on us we can’t do all. There even there should’ve been people from somewhere that very work for us. Then after we done some they will continue for us, then go some. So that the mothers wouldn’t be depressed when they go home or something.

I: Ok, so just so that I’m sure. So like the counseling, if there was one, here the counseling unit

P: It’s just pediatric.

I: They could come and talk about whatever they are having problems with and extra education. But when they come to bring their babies for review, that’s like a check-up. Just checking to make sure that that baby is ok.

P: Mmm mmm yes.

I: Ok, um so what what is usually the reason a baby doesn’t survive after a near miss? Or let’s say, they make it when they looked they were gonna die but then they die later, what is usually the reason that happens?

P: Uh you take care you thinking this baby will survive, then it goes. Hmm maybe in but that one is. Hello! (person interrupts).

I: Keep talking.

P: Maybe we are giving all the treatment alright we are feeding everything was going alright but all of a sudden you come and they die. It’s difficult to tell, it’s [inaudible-27:34] it’s difficult to tell. Because we do everything we can do. But we go come and then babies died. So it’s a problem and its difficult to really pinpoint what happened.

I: Mhmm ok. Um so what do you think is needed to increase the number of babies who survive?

P: Hmm, funds. As I said we we we should get everything once if not all. Almost all that we need. Like now we having problem with oxygen. That wall oxygen goes and comes, goes and comes. Hmm goes off, I call them the tech come in they have a problem over there with the plant, it has effected. Meanwhile, we have babies on it. Pediatric medication, treatment is not available. Babies who come, mothers who have to go to town look for it. If they don’t get it, even fluids we don’t have the pediatric dosages of fluids. At the moment there very one we use is not available. We have to be mixing. That one for is not available, we have to go and buy and then we do the mixing. So these are some of the issues you get every time. Or our drugs aren’t ready or oxygen isn’t ready and then um eh we have machines, respirators, ventilators ventilators and CPAPS, we should have used them but eh oxygen to connect them is not available because the hospital thinks they want to build a new NICU. And we haven’t gotten sponsors to build it for us. So the machines are lying there and babies are dying. So we do all we can but the machines be sitting down. Over one it’ll be dustin’. So if we should get all these machines working and then the tech can become available, pediatricians who ready, specialist available to do the work. I think it will reduce the near miss babies. Their survival rate will be higher then as we are getting mhmm.

I: Ok, um so do you have any other comments about babies who have experienced a near miss and their care that you think is important for us that is doing this research to understand?

P: Hmmm in fact, some of them they do, they make it. They do make it. They will come, you try and severe apneic attack then they survive. It is, sometime we say it is God. It is not our making it is God’s own intervention. Because somebody say the battle is not yours the battle is the Lord’s. Sometimes it is God who has incited some of these battles for us. And then maybe we also did our best and then the doctors as I said earlier when they are around and we all do our work well we’ll think when they are not around. Sometimes when the house officers they are fresh ones they come around they [inaudible-31:07]. There wouldn’t be any senior man to supervise them. They don’t know anything about pediatric and then they come and handle babies. So if you, the senior nurse, you are not around until cause a junior doctor with a junior nurse, what will happen. So we try to do whatever we can for these babies to always survive and we are happy.

I: Ok. Well again, thank you for your time for answering our questions. We hope you answers will help us understand more about why babies that seemed as though they would die, live instead. Please let me know if you have any questions.

P: Mmm, so this research, what will it will it benefit the ward? How it will it help us also too…

I: Mhmm well…

P: Increase our survival rate for near miss?

I: Mhmm, well kinda depends on what we find. If we find something useful um so there’s people that, we’ve ben doing this research at multiple sites and so there will also be a follow up study so were trying to collect enough data to let you know if this is useful or not. So we will be, once it’s published and known to be something useful, it should help the ward. Like we’re hoping that it provides direct use to you all.

P: Ok. So is it going to be just once or will it be continued?

I: Well there’s going to be a follow up study for a year. On cause there’s other you know this is part of the project in which they are collecting information on near miss. And so they’re it will still be going on for the next year.

P: Ok, mhmm.

I: OK, so if you have any other questions in the future, I can be reached. You can reach me through \_\_\_\_\_\_\_ who you met. Um and so she will have my contact info and you can also ask her questions as well. Ok. Also, do you think…

END OF INTERVIEW

Type: HCP Interview-KA9011

Date: 02-07-2015

Position: Nurse

I: Thank you for taking the time out of your schedule to meet with me today. Um, as I’m sure you’ve been told, this project is focusing on learning more about the babies who have life threatening complications during and after delivery, but who survive. Your thoughts and opinions about why some babies survive while others die are very important to helping us understand these issues better. As a reminder, I will be recording the interview. This is just so that I have something to help me remember what we talk about. It also means I won’t have to take a lot of notes, just stuff that we need to follow up on. Just so you know, the recordings will never be played publicly. We will transcribe them and then destroy the tapes. If there is anything you don’t wanna talk about, please let me know. Also, we can stop the interview at any time. Please let me know if you would like to stop. What we talk about will remain confidential. I won’t share the details with patients or others at the hospital. You will not be named in anything that is written about this research. And just so the tape knows, this is interview KA9011 (siren in background). We would like to learn more about your experiences with babies who are ill and their outcomes. You’ve been working on this NICU for \_\_\_\_\_ now and some of the babies have had severe complications. Some of them, you may have struggled with and they died. Some of them, you may have struggled with and they lived. Some died no matter what you did. Some lived when you thought that they were going to die. What do you think was the main difference between those who lived and those who died?

P: Well, um. Those who died, some of them, they come in a very bad condition. Like, severely asphyxiated babies or babies with very bad fetal distress. Those people who usually they die, even like, no matter what we do, they die. However, some those who live, maybe they are brought in quite early. There’s no delay in bringing them to the MBU here to seek help. So that’s the reason why they live. And some of them are seen, like, the management is good. And also those who died, maybe their prognoses are already bad. So technically they will die. And some of the deaths too, I would say, um a delay in taking action. Like, taking prompt action. There’s a delay that can cause the baby’s life. Sometimes we don’t have the real information about what actually happened to the child. And they also die. Because some of the referrals come, we don’t have detailed information as to exactly what happened and they die (car honks horn). Yeah, and some too, they are even sent home and they are brought back. They are discharged home and they are brought back. The mothers don’t have adequate information as to how to care for their baby. As to see if the child is ill, the baby’s ill the third one week of the baby’s life. And the mother comes like this jaundice, severe jaundice, they come in kernicterus and they die. So it all stems from information to put the health workers at the peripherals those with them (3:08) and then to the mothers or parents.

I: Can you tell me about your experiences with those babies who lived when you thought they were going to die? What diseases or conditions did these babies have?

P: Those, um, babies with severe asphyxia they come in, they come in. There was one situation, the baby came, the baby, I thought the baby would die. We kept bagging, resuscitating, resuscitating, resuscitating. The baby survived. He couldn’t really suckle the breast but (rustling). He couldn’t really suckle. We we had to feed NG tube. So eventually the baby was ok, he could take some things and then take the breast milk but couldn’t really suckle well. But was ok, the baby was discharged home. But after a year, I met the mother and the baby had passed away.

I: Uh huh

P: Yeah. And she also complained that the um the development milestone was delayed. That’s right, she swayed from the normal like a extreme how as the baby develops, sitting up, talking, mama, dada. She couldn’t say those things, I mean, it was delayed. The baby didn’t walk, even after a year, the baby died. So that’s what I mean, those are the things that usually happen to these babies. There are others that come with some conditions and because of financial restraints they don’t get what’s, like, the medications and other things. But they survive eventually. They’re ok, they’re ok. Some of them are grown now. So it’s all depends on. And sometimes I believe it’s God. God has a way of you know dealing with people. If he wants you to live, you’ll live. But, that’s it as I see.

I: So for the babies that survive and then later on die, what do you think is the difference for those babies? Like, why do some still survive versus some end up dying later?

P: Those who survive, maybe their condition was not that bad. They didn’t have very bad prognosis. But others, maybe, like, they do-they don’t get the, they don’t even come for review. The parents don’t even bring the babies back. Here in Ghana, people think of, like, spiritual things. They want to seek help from God and do things. So they concentrate more, yeah, we have the thing ‘spiritual diseases’ that they talk about in our society, in our culture. So they understand that maybe this child is suffering from those and then they seek herbal help. They seek their their their traditional priest and they eventually they die. Instead of coming back to the hospital as scheduled. Come for review, we can refer you to the specialist and there’s an ongoing review, but they don’t come.

I: Um, are, is any special care given after these diseases or conditions are resolved while the baby is still here in the NICU?

P: If it’s resolved, yeah we continue. You know babies are supposed to take in enough food and the breast milk to survive, to grow. So when the baby’s condition is perfect, we start with NG tube. We want to make sure that the baby is taking in enough breastmilk. We help the mother alongside cuz the mother has been through with the most with the child. So we help the mother alongside to get enough breastmilk. And the baby takes enough. Like if there’s any hemolytics (?), we need to prescribe or something, we give. Then we keep checking the weight alternatively to see if the baby’s gaining weight, which means that the baby’s growing. So basically that what we do and we prepare them for discharge. Then we teach them how to take care of the child as they go home. Then we ask them to come for review. So that’s what we do. When the baby survives, the baby will not leave here without gaining weight, no. Usually the baby gains weight. At least, gains the weight that it was born with before going home. So that’s our aim.

I: Are mothers, ok so, are mothers typically given special instructions for caring for babies that live that you thought were going to die?

P: Yeah, they are given. Some of them are told exactly what will happen. Like, what they should expect. If if the baby is is severely asphyxiated, what you’re supposed to expect. The baby will not develop as other children might have. And then their eating habits. You know, their taking their foods. So you teach them how to be slow, to be patient with the babies. So that’s the difference. We teach them what they should expect and what they can do to help the child.

I: So do you feel like the mothers usually understand these instructions?

P: They do. While they are here, they understand. When they go home, they have other doctors around. You know, uh, home doctors. Our grandmothers, our relatives at home. They teach them and they influence what we teach them. So if the mother is not so strong, is not educated enough, I don’t know, I have to listen to the doctors and the nurses, the professionals. They would speak to them. And it will mix the whole thing up. So for some it can cause the life of the baby. But as for the home, its influences, whatever we tell them. But when they are in trouble, they rush back. So that’s what happens. Some of them get home say ‘oh, stop, lets give herbs’. Not the herbs that the pharmacist has really sat down to do the like like, what is, like its composition, no. They measure the right amount. No, they give normal herbs. They don’t even know how the liver is going to take it. So they just keep on giving them. Those babies die.

I: You said the give what? Health?

P: No, herbs. Herbs. Herbs. These traditional herbs, like plants.

I: Oh, ok yeah.

P: Yes. Yes. That’s what they give.

I: Ok. So when moms don’t follow the instructions, what do you think is usually the reason why?

P: They don’t follow the instructions?

I: Yeah.

P: Sometimes they don’t trust what we are saying. First of all, Ive seen that they think that it’s otherwise. We see that something that is happening to the body of the baby is physiological so when we help it, no.They think it’s spiritual so they will move to the spiritual side. And most of the time the spiritual side goes to the herbs. They listen to other people’s advice. “Oh, it has happened to me before. I think it’s this one. Don’t listen to them. Let’s go to this place.” And they keep moving here from one place to the other. And there’s a confusion in the care of the baby.

I: What do you think can be done about that to help prevent that kind of problem?

P: Prior to delivery, and to base more on the obstetric and gynecologic department how to be deliver the ANC, antenatal care. You’re supposed to give them all this information. Just to tell them. You know most of our mothers are illiterate. They they don’t read. If they’re able to read, take their books when they are pregnant and pregnant for the third time, I have to believe, I know what I am supposed to expect. So if they do that, I’m sure it would help. And when they come here to, they they they’re supposed to really tell them as soon as they come. If the baby is asphyxiated, tell the mother, this is what is happening. That’s what’s to expect. The baby can die. Most of the time, we are slow in action, in telling the truth. We don’t really tell them the condition cuz sometimes they come here, “Discharge me. I want to go home. Discharge me, you are wasting my time.” But they don’t know that this is what is happening to the child, the baby. So I think if we are really telling them the truth, they would have sat up and then they’d have agreed and listened. But because we don’t tell them right from antenatal to postnatal, we don’t tell them exactly what’s happening to their baby, they think that they are fine. So why are we worrying them. Eventually they go home and it’s a mess. They come back and it’s too late.

I: Do you feel like there are, or, err, well what culture barriers do you think exist to giving mothers instructions for these babies?

P: I’ve already talked about it. I said eh you know our home set up. We have extended family. It’s not the nuclear type of late (11:37). So they will come and give you, your mother-in-law come and tell you, “Oh, let’s do this.” Even when a child is born, even the umbilicus, you know. You’re supposed to just dress with spirit (11:47) and keep it dry. They go home and it’s a different issue. Some of them will go for cow dung. You know cow dung? Yeah. They go for cow dung? Some of them will take salt. Very concentrated amounts of sodium and put it on there. Some of them will cut it and some of them will use paste. You know, paste? And they put it on there and they smear it, they smear it all over. And it becomes infected you know. So there’s a difference, people see babies and they think they know how to take care of the babies more than. So those are cultural practices. They think if a baby has an umbilical and its not gone by three days it should be off. So why should it be there? It shouldn’t be there? And they go for lots of chemicals and put on the baby and some of them might survive. Maybe they did it to me. I don’t know. I have survived so why is it that this baby’s not surviving. But know, we are different. We are unique. So some of the babies die when you do this to them, others have survived. So that’s the barrier, “Why-o this child has survived, so this child must survive.” And they keep doing it. So that’s the cultural barrier. You have a lot of practices, the beliefs, religious beliefs and that affects. Yeah.

I: Have you ever discussed one of these cases of babies that survive when you thought that they would have died with a supervisor or a coworker?

P: Yeah, like we. Yeah, I I I have. We just talked about it. “Hey, this child, I knew this child would die. But this child has survived. And thank God for maybe the effort that we put in. Maybe, we we are very vigilant with this child, the care of this child.” So that’s what happens, yes. But but, like this, but like this MBU in particular, the workload is too much. So normally there maybe babies that should have died but survived. But mostly they die, because the workload is too much. Because in about one nurse to about 50 babies. It’s impossible to have quality care for these babies. So there’s a lot of miss, you know, maybe miss the death and then they survive. It’s less. It doesn’t really happen. It doesn’t usually happen. Unless the condition is good, then we just help the baby through. But in very bad cases, severely asphyxiated babies, babies it doesn’t really happen that they survive. No. They die. Once in a while you get one. And that one may be a health worker’s baby or something. You know, and now on everybody’s mind is this baby. Or the mother is educated and keeps asking questions. And they know that if you make any mistake, you are in trouble. So now on everybody’s mind is on that child. And you keep helping, you keep helping. But but it’s rare to get this miss.

I: And what do you feel like could truly be done about the problem of the workload?

P: Hmm. I don’t know, I don’t know. In fact, I I don’t know. You’ve been telling the survivor the eh stakeholder to bring more nurses but the government doesn’t want to take any more nurses, to pay more. So we are really struggling here. Sometimes you come, you want to do it all but you can’t. Since you are human being, you are limited. You want to take care of the babies (makes noise indicating no, no, no). Even where I work, the preterm unit, you would wish that you can keep the babies warm, want to provide everything. It’s not there, it’s not there. So the mothers go through a lot of pain when they come here. And most of them they break down. They get depressed, they get psychosis. So we take them to psychiatry unit.

I: Mhmm

P: So because the baby’s a preterm baby, you need more time for this child. But the mothers are going through a lot of stress. The nurses are going through a lot of stress. So most of these babies aspirate and die. Can you believe it? Just aspirate and die. The babies, some who are who are on oxygen, but because of the number of babies in that particular cot taking oxygen, you notice that the one’s oxygen is off. So you come back, the baby’s dead. So that’s what’s happening, I mean, happening thing, a very bad situation. The workload is too much. So you don’t really get the miss the same. When we miss some of them like they don’t (16:13) they survive. You don’t usually get that that much.

I: Um. Hmm. Ok. You said, darn. There was something that I was gonna follow up on that you said. We’ll keep going. Uh, so when you and like members of your team discuss these cases, what is usually the outcome of the discussion?

P: When we discuss about those who survived?

I: Mmhmm

P: Hmm. I mean, what I’m saying, they are saying that we but in much effort. We did very well. We made sure that the child had everything. When the child begins to become cyanosed again we resuscitate. Maybe we are there 24/7, resuscitate. We are there, we are working very hard to make sure the child survived. That’s what I’m saying, it’s rare, it’s rare. When we discuss, then we will give council. Then we’ll all say, “oh we wish we had enough nurses to do more, you know. Enough doctors to do more.” So we keep missing them. They keep dying. Sometimes, you come on duty, six of them gone. Meanwhile, maybe they, I mean, they shouldn’t die. I mean, some die of hypoglycemia. Can you believe it? Hypoglycemia!

I: Right.

P: Because we are not. I mean, we cannot do the RPS as often as we should. (17:37) We are bagging this baby, you forget. By this time, the baby is gone, yeah.

I: Ok. I remember what I was going to ask about. You said a lot of the mothers end up stressed out when they’re here

P: (Exasperated sigh)

I: And they get psychosis. So, um, are they typically like screened for postpartum depression or is it just usually it’s so severe that that’s when you know to send them to the psych ward?

P: Hmm. It’s so severe, we don’t screen them.

I: Mhmm

P: You know, they they come from the obstetric and the gynecologic department. After delivery, the mothers have. And the babies are not fine, they are brought to MBU. So we meet the mothers when they ok, then they are discharged. So they come here to take care of their babies. When they come and they see the state of their baby. Because it is said that as soon as you deliver, you should go home, get people around you to help you nurse the baby. So that you can have enough rest. But when you get here you can’t rest. I I did it at my unit. You’re supposed to come there two hourly. Every two hours to feed the baby. So what when do you rest and they are clustered in their room, about hundreds of them in one room. Look at, they can’t sleep, they eat in their room, they pee in their room. They’re living there like prisoners. One mother said the room is like a prison!

I: Mhmm

P: Said that where you keep them its like prison. But it’s not our fault, the small room are also suppose to be there. We cannot say we wont take it if your baby, no. So that’s what is happening. So they break down because they don’t go home, they don’t have enough rest, they don’t understand what is happening to their baby.

I: Mhmm

P: And they start talking incoherently, you know. They start hallucinating. “You are going to kill my baby! Give me my baby. I want to go.” And they start to scream. There was one issue, the the the mother just like jumped off. She was just about to jump and commit suicide.

I: Oh, gosh!

P: Oh sss, that day, it was terrible. She she she’d been through a lot from the O&G department, maybe the Cesarean section, with the pain. She comes out… Where does she rest? The room. And there, their pain management is very poor. One day, they discharge you, that’s all. So when you are going through anything, they don’t care. And the mothers have lot of pain and they come and take care of their child. Coming every two hours. Get up and go to the room and don’t have a place to sleep. They break down. So we keep taking them down. We keep giving them medication to rest. So that’s, we don’t screen them. But when they come, I’ve learned from my experience, when they come, when I talk to them. As I talk to them, I just, I’ll look into your eyes, straight up. Then she’ll start looking somewhere and she’ll start saying (sucks teeth) “I don’t want to come.” You realize that there’s something going on. Just be there about two days and she breaks down.

I: (pause) Wow. Ok. Have you ever received formal training on how to handle these cases of babies that survive when you thought they should have, they would have died?

P: No, I haven’t had the opportunity to do the neonatal nursing. Because you you have to travel. Ehh and my family, I haven’t tried doing it because I have to travel. I can’t leave my kids. But I’ve learned on the job. So that’s the training that I have. And I’m doing my best.

I: Mhmm. Do you feel like there should be more training on how to handle these cases? Like maybe inside the hospital?

P: There should. There should be more training. It’s to help us, it will help us. At least we get formal knowledge, you know. What is exactly what to do.

I: What kind of training do you think would be useful for them to do, like, in the hospital on how to handle these kind of cases?

P: Oh, neonatal care, like resuscitation, erm basic things, basic things. And then what to expect of the conditions. What do you expect, what to expect in a particular condition, what do you expect. If the nurses are away you will not wait until you know, uh huh.

I: Mkay. So just in general, what do you believe is the most important thing to understand in order to handle these cases of these kinds of babies?

P: The most important thing to understand is that, um, if you know that these bab—ehm, babies that conditions (?22:02) can survive. So when you’re putting your best, the baby can survive. So if you have this at the back of your mind, I am sure you know, like, oh you put in your best. That these babies (whispers remaining sentence).

I: Mhmm, what do you think is the most important thing for mothers to understand when their baby is getting discharged? Like, just the overall thing they need to know.

P: They need to know what happened to the child. Why their child was brought to the MBU. What happened, which medication has he taken so far, and what the mother should expect when the ehh the baby’s sent home. And then they need, the importance to come for review. Come back as scheduled. And even if there’s something happening without even when the scheduled time is not is not on, they should still bring the baby back. So I think that’s what we should. And the need not to listen to, you know, our home doctors to confuse them. I think that’s what we should tell them.

I: Mhmm, ok. Are you familiar with the term near miss?

P: Near miss? Yeah.

I: Can you tell me what it means to you?

P: Like if the baby that you think would die hasn’t died and the baby survives, you know. That’s near miss, I mean.

I: Mhmm, do you think uh healthcare workers all have the same idea of what a near miss is?

P: I don’t think so. Most people don’t know. They don’t know, they don’t know. But if a child survives, like, you really think this child should have died. This one. If we are going, “Oh by the time I come back, this child will not be there” but it comes child is still there and even doing better. They don’t understand. (mumbles another comment).

I: Ok. So even, let’s say, they might not know the word near miss,

P: Near near miss

I: do you think that they distinguish ‘oh this baby survived when it looked like it wouldn’t?’ Do you think they distinguish that from other babies.

P: Yeah, they do. They do but they don’t know that the, the name is near miss. They don’t know. But they they think it’s sometimes happens.

I: Mhmm, mhmm

P: That’s all

I: Ok. Do you think it’s a distinction that’s useful for healthcare workers?

P: Yeah. It’s very useful. If we have this I’m not, I’m sure most babies would go through near miss. If we had this at the back of our minds. Putting more effort for them to go through near miss.

I: Eh, so if you knew a baby was classified as having a near miss, do you think it would change how you managed that baby?

P: Yeah. Yeah. I think it would. Let us sit up and then you observe the baby more. You get to interact with the babies and the mother very well. Then you’ll always be probing to find out what’s happening to the child. ‘Is the child ok? Is the child doing well?’ You just want to know, maybe even with when the child goes, we just want to find out. Sure, it will help us with the continuity of care, even outside the hospital.

I: What challenges do you think babies who experienced a near miss will face as they age?

P: Usually, neurological because we keep bagging them. You know they’re bagging, AMBU bag and its not the best. Keep doing it over over 20 20 minutes, we keep because we want this child to survive. Lots of oxygen, adrenaline, the babies they wouldn’t survive. I’m sure if if if it’s God’s will for he is the ultimate. You know, he can decide that this child should live. But most of them that live, they have developmental problems.

I: Mhmm

P: Some will bring, show signs of autism. You know, they don’t talk, less speech. They are slow. Not intelligent at all when you compare them to their peers; their age group. They are slowly understanding whatever you are saying. These are the things that the parents must be told.

I: Mhmm

P: And they need support. But in Ghana our system here is not up, we don’t have that kind of support for those child who are dis, like, disabled, that are deranged. We don’t have the support for them. So that’s what you would be expecting. The near miss. They have near miss, they’ll be having problems in future, but if they had the support, they’d be they’d be they’d be okay. We don’t have the support.

I: Mhmm. So, so you feel like the healthcare system doesn’t necessarily have the support for if there’s neurological problems. Do you feel like there’s support for other complications that come out of near misses?

P: No, there there isn’t any support. I don’t think there’s any support. Usually if it’s a near miss and the parents are rich, they might come for review, going to the neurologist, and then they will take you to neuro and then you can pay. You know, you have the money. But most of them are not, they don’t have the money, no support. Maybe they will be asked to stay at home. Once they are there their (27:07) are going to scream. They will stay at home, they can’t do anything. They don’t have any support. The health system don’t have support. Cause you would love to help these children. But where is the money? Maybe in future, they’ll be asked to take MRI. You know. How can you pay for it? They need special school. Where? Unless they’re rich.

I: Mhmm, ok. So, uh, what do you think is needed to increase the number of babies. Like, so, you know, there’s babies that look like they’re going to die and some live. What do you think is needed to increase the number of babies that ended up living that when they look like they’re gonna die?

P: Um. A little bit information, like, we should erm, educate or train the healthcare workers. And then enough healthcare workers. We have we need enough human resources. And then enough resources, infrastructure to put things in place so that we get more of these babies. That’s the pre. And then, then the post, we need support. I mean, to support the parents and tell them the truth. What they should expect. And then, that’s what basically. We need before, like before before before they leave the hospital, we need those things in place to help them survive. And when they survive, after they have survived, we need to support for them to also go and fit into the society as they are suppose to. In the long term, we have a short term, long term.

I: Um so what did you mean by infrastructure? Like what kind of things are you talking about?

P: The things maybe emergency drugs, the ventilators. You know, you can’t be bagging, bagging, bagging. We need ventilators.

I: Mhmm

P: We need incubators for our preterm babies. For our babies with low birth weight. They don’t have enough at the post, usually they lose heat. We need all those things to keep them up. Enough, em AMBU bags, sometimes, you know, even there arent enough AMBU bags for them. The pre, I mean, the preterm baby. We have to use the term baby’s ambu bag. We usually are hyperventilating the lungs. So a few of these things. We go through a lot.

I: Mhmm

P: We need the the, I mean, resuscitate the whole equipment. Sometimes you you get to them, you don’t have some of the equipment and things. So all these things, we need them. Enough doctors, enough nurses.

I: Mhmm, ok. So do you have any, like, so anything else that we may have not touched on or covered about babies who look like they’re gonna die but they make it? Just any other information about them that you think we should know for this research?

P: Mmm, I think we’ve covered a lot. Yeah. Like the big thing is that if maybe we have like have to support the parents, that is the basic thing. Because sometimes sometimes they, I mean, they just near miss but they can’t go, they can’t go far.

I: Mhmm

P: Near miss leaving the hospital, they go home. ‘oh, how’s the baby?’ ‘it is gone.’ The support after, is the part. If we had some funds to help them, like, to continue the care. Because we don’t have, we have the near miss period. You ask of the child, the child is gone.

I: Mhmm

P: After after after discharge. I’m sure that’s what we should hit on. Post-care.

I: What other, like, what other kind of support do you feel like the parents need once the baby is discharged?

P: Maybe we should have um a group support. Maybe this kind of, like, we form a group where we teach them, we encourage them not to go back (?30:59). And then for the special schools: We don’t have enough in Ghana and then when you go there, it is bad. Their nutrition is not good. So is that a special school, no? Hmm. So that’s why parents don’t want to take them to the special school. They want their child to go to normal school but it’s not working for them. Also, then we have a school for autism only in Accra and it’s very expensive. So what if the child becomes autistic?

I: Mhmm

P: So these are some of the issues. I mean the country or Ghana or whoever when this it happen, we have those kind of facilities for them. I’m sure the parents would be ready to help.

I: Mhmm, ok. Well again thank you for your time

P: You’re welcome.

I: And for answering these questions. We hope your answers will help us understand more about why babies that seem as though they would have died live instead. Please let me know if you have any questions.

P: I don’t have any questions. Ok.

I: Um well if you have questions in the future I can be reached through Dr. \_\_\_\_\_\_. Uh she has my contact info. Also, you can ask her questions directly as well. But thanks again.

P: You’re welcome.

END OF INTERVIEW

Type: HCP Interview-CC9014

Date: 16-7-15

Position: Nurse

I: Ok, uh thank you for taking the time out of your schedule to meet with me today. As you may know, this project is focused on learning more about the babies who have life threatening complications during and after delivery, but who survive. Your thoughts and opinions about why some babies survive while other die are very important to helping us understand these issues better. As a reminder, I will be recording the interview. This is just so that I have something to help me remember what we talk about. It also means that I won’t need to take a lot of notes, I will just write down what I would like to follow-up on. Just so you know, the recordings will never be played publicly. I, we will transcribe them and then destroy the tapes. If there is anything you don’t want to talk about, please let me know. Also, we can stop the interview at any time. Please let me know if you would like to stop. What we talk about will remain confidential. I won’t share the details with patients or others at the hospital. You will not be named in anything that is written about this research. Also just so it’s noted on the tape, this is interview CC9014. Uh, we would like to learn more about your experiences with babies who are ill and their outcomes. You’ve been working on the NICU for about \_\_\_\_\_\_ now. Some of the, and some of the babies have had severe complications. Some of them, you may have struggled with and they died. Some of them, you may have struggled with and they lived. Some died no matter what you did. Some lived when you thought they were going to die. What do you think is the difference between those who lived and those who died?

P: What is the difference between those who live and those who die? Um. The babies who live, um depending on the severity of their condition as of when they were admitted. Yes. Um it also depends on how early or how fast they were resuscitated. It also depends on the, on the um the, the manner in which they were transported to the unit. That is if they were from outside. The the way and manner and then the duration that it it spends. It also depend on um whatever they have been on before they got to the health facility. Yeah. Some sick uh look at uh ca—healthcare sort of look, they apply oh lots of other alternative uh um medicines. So it depends on that. Um um others other others um with all this, others survive through um the villages of maybe health health health personnel. You know they come, the way we receive them, the way we promptly put in the the measures to really save their lives. You know. Others also uh the health personnel may, might be waiting but maybe the facilities might not be there. Other times, the, every time you receive them, you have everything. You have the drugs, you have the facility. Today, for instance, there’s no oxygen in the hospital. So if you have the baby come in, rushed in, apneic or blue or severely asphyxiated, I don’t know. This morning we nearly turned one baby away because of lack of oxygen. The room was booked up. You know, so these are some of the things. So um, most babies survive when these things are in good shape. Some will die because these things are not properly—either they are not there or maybe they are not in good shape. And some will also die cuz maybe the [inaudible-3:54] will maybe have applied a whole lot of things which were eh either harmful or not necessary to really solve the problem, yes. So these are, these are, these are the things.

I: Ok. Um, can you tell me more about your experiences with those babies who lived when you thought they were going to die? What diseases or conditions did these babies have?

P: Yeah. Um, let’s take a severe birth asphyxia. You know, sometimes the babies come and the uh well this baby is not going to live long. Uh the baby comes, having multiple seizures, uh hypoglycemia plus plus plus. Um uh having intermittent or—I will say intermittent—apneic attacks here and there. You know, uh maybe relatives not cooperative because they think they baby is sick and so they shouldn’t be invest so much in the baby. And then you think this baby is gon—is not going to make it. But erm uh we put in one or two, whatever we have, whatever resources we have. We try to put in here and there. We try do uh very good monitoring with the little equipment that we have. And then um uh sometimes we go to the extent of even contributing. Us as health—contributing to buy the drugs. You know, and then we also, I personally have done: I’m a counselor and um eh that is a counselor in the health counselor at church ?and all?. And so sometimes I have to also bring in the spiritual. Take care of the spiritual aspect of the family people. Tell them um God is able. If they are Muslims, I direct them to their Imam, the strength. So we combine both physical and spiritual. You know, in Africa, we believe uh certain things are spiritually ?learned, God?. So if you realize that the the the families also have that idea, you need to really, you need to disabuse their minds or tell them to go to whichever spiritual eh eh spiritual authority that they believe could help them so that they engage themselves in prayers or whatever, you know. In addition, and then we also, as I said, we do contributions or we ask for donations to help buy the drugs. And eh miraculously some of them survive. You know, a number of them make it. T-t-t-they just make it.

I: So like for the babies that end up not making it, what do you think is the difference in the ones that do end up making it when they look like they wouldn’t? Like what is the difference for them?

P: What is the difference between those that make it and those who they don’t make it?

I: Mhmm

P: Ahh maybe at a point at time the health personnel might be tired. We don’t have money. We cannot go on being there using our meager salaries, you know, to—here, maybe elsewhere they pay for you’re your your, I mean there are other ones maybe your your your transportation, your lunch um sometimes we take care of other things. You know, other ones. But here, your salary’s what you get at the end of the month. So uh if you don’t have that kind of attitude, that kind of character; you want to go the extra mile, you have that kind of pity on children, you’re not going to contribute for aiding them. You got it? Good. So we’ve contributed today and then the next day another one comes. You know, people just throw their hands in the air. “I’m tired. We can’t.” So maybe the drugs will not be bought. Uh maybe relatives also cannot afford it. So maybe we will end up losing the baby. Other times, maybe the facilities are not there. As I said, today in our ?ward? there’s no oxygen. A baby might come, we’ll be ready to get the drugs. I mean, babies so blue, so asphyxiated, the baby needs. Baby goes off and on. We need to resuscitate the baby. Oh um AMBU bags but not proper, in good shape. Our oxygen is not working. Maybe our pulseox (/pulse oximeter/) is working now. I mean, so everything, at a point is that everything can just go bad. As I’m talking now we don’t have 10% in the hospital. Uh we don’t have uh one fifth in [inaudible-8:45], eh one fifth [inaudible-8:47] and ten percent we don’t have. So relative will have to go and buy. Other lines like third line antibiotics like [8:52—drug name] and other things we don’t have. And they’re expensive. They can’t afford. You know, some even can’t afford the insurance. How much more you tell the person to go and buy drugs. So they go and they don’t come back. We’ve lost a baby this morning. The relatives don’t come at all. You know we suspected uh eh the eh stenosis of the of the stomach, you know. So we told them they had to refer to \_\_\_\_\_\_ because there is no pediatric surgeon here to fix that. They said they can’t go to \_\_\_\_\_\_. Even the little little non insured drugs they’ve not been able to pay until now, so we’ve given them out free. I have to donate my my colleague uh Senior Officer to have to donate and now they are tired. So the baby passed away this morning. The parents who cannot afford even the transportation. Even insurance they don’t have. How much more afford them take the baby to \_\_\_\_\_ for. Meanwhile it could have been fixed. Yeah. Literally you get there, you, they have operation. Since it’s an emergency, they just add the baby to the list and it would be done. You know, those who go to \_\_\_\_\_ the ladies say, “It has been done, my baby’s doing well.” You know, so financial constraints is the biggest problem. Financial constraints. And then with the hospital facilities and then to get the drugs and equipment always working because with that, so that is the difference. Some babies come, they are fortunate, everything is working perfectly. Maybe they are fortunate, they have parents who are working, you know. Other babies come, everything has gone bad, you know. And so this is the difference, you know. This is it. This is bad. This is bad. Unfortunate.

I: So when babies look like they were gonna die but they live instead uh from whatever intervention is given, is any special care given after the diseases or condition is resolved?

P: Any special care? Like?

I: Just anything else you make sure you’re doing because you saw that this baby almost died. Is there any special care you give because that baby almost died?

P: Well, if if if it’s, if it is necessary. If it is needed. We give it. Uh what I normally do, I counsel the parents. I give them a lot of counseling. You nearly lost this baby and you are aware. From the day one, you told me the baby is 50/50. The baby can make it. The baby can go. So miraculously, the baby survived through one or two interventions and then, you know. So it’s counseling. Yeah, you know, I just, just take good care of the baby. Put in all the resources that you have because we nearly lost this baby. If the baby uh survive with other complications, we tell the mother. Like severe uh birth asphyxia, most of them will end up, or severe jaundice with kernicterus, will end up with CP, cerebral palsy. So we tell the mothers the baby is likely to have this. You know, we don’t know how severe it will be but eh so anytime you and your baby have gotten to six months, [Inaudible-12:29]. Or baby is not able to talk well at maybe eh one year. You know, we give them the signs. They should know that it’s because of what the baby went through. It is a narrow escape that the baby he didn’t die--he or she didn’t die—but he’s bound to have this kind of complication. So look out for these and when you see them, report and let’s help you, you know. And then we also give the mothers how to care for the babies when they are discharged. You know the baby uh passed through all this. It’s not like any other baby. Sucking will be a little bit difficult, too. You have to do a lot of cup feeding. You’ve got to [inaudible-13:10]. You’ve got to do to keep your baby going. You have to be more gentle on this baby. It’s not going to develop like the other babies who maybe do this ?here?. So we do a lot of counseling. We tell the mothers erm eh how to take care of the babies and how they should be prepared to expect or they should expect any complications and then report promptly. (mumbles another statement)

I: Ok. So besides like what you were talking about for what you teach the mom, are the mothers given any other special instructions for caring for babies that live but that you thought were going to die?

P: Apart from what they are told?

I: Besides um the feeding…

P: Counseling?

I: Yeah. Any other special instructions you give?

P: Uhh it would be it would be on the feeding. You know the counsel is all-inclusive. It covers the feeding, the care, the medication the mother take home, eh expectations of communications. Um it’s all-inclusive. Um exclusive breastfeeding, I mean, it’s all-inclusive. We touch on everything that we think it will be very necessary for the mother to take care of certain babies. And it’s (mumbles).

I: And so do you feel like the mothers understand the instructions?

P: They do. They do. They do because they keep on asking questions and questions and questions. They do. And then sometimes their partners will also come in, ask questions, and they and they will go and let you take your number. “Miss, I want to take your number so that uh in case there’s a problem, I can give you a call for clarification.” So that shows they really understand and they really want to uh, do all that they can to keep their babies healthy. Yes. Asking questions and then picking your number. Some even want to know where you stay so that, you know. Uh the stress here, I cannot take it home. So normally we say the number is ok. When you are worried you just call.

I: Ok so if you ever noticed a mother doesn’t follow the instructions, what is usually the reason why?

P: Um unless the mother reports we wouldn’t know whether if she’s following the instructions or not. I would say about um about 40 percent of the mothers come back. They come and show the baby to you, how happy they are to see their baby’s still alive. You know, the stuff. About 60 percent, you never see them again. You know, you never see them again. And I think that is where there is a lot of problem. We should have eh a system where the community health nurses would have followed those mothers up. You know, but again for lack of stuff, constraints, and financial obligations of the hospital; no, you don’t get those nurses to follow the mothers up in the community. So we lose touch on those who will not come themselves for follow-up in the hospital. I mean, you lose touch. But about 40 percent have come back. You know, and uh some we realize that they have followed the instructions to the letter. You see the babies doing well. They tell you, “I’ve started, I-I-I’ve noticed this and that in the baby.” Or they say this and that and that. Some will come and you realize that the baby is not doing all that well so you need to reinforce your counseling. Ask why she’s not doing this or she’s not doing that and that is what is causing the baby—Sorry. That is what is causing the baby to maybe develop this or that or that. And they will also give you their explanation. Why they aren’t able to do that, you know. So again we just put in counseling. You know, you put in counseling. We are. There are a few cases I have followed up to them, to their homes, yes. Because uh I really want to see the babies live and I realize that they have a better eh eh they have a better eh opportunity to really make it. So there are a few instances I’ve followed up to their their house to see what actually is going on in the in this place. And uh you learn that it’s just a few problems here and there so you get them fixed. And ‘cause sometimes you’ve got to invoke even the family members. You know, as Africans, our extended family is part of us. We are married. Even when you grow old, they are still part of you, you know. So you’re aware that the person is staying with the whole family. Go, the grandmother is there. The the great granny is there. Everybody will want to handle this baby in his or her way, you know. So you put all of them in the counseling and give them uh a little of bit of background. And then the next time you see the baby he’s doing well. You know, financially. You know when they understand the principle eh eh the rationale behind why this baby should be treated this way, and even get to know that this baby, even though eh it’s so sick, he can become somebody in future. You know, they begin to contribute. They are [inaudible-18:51]. We realize when the financial problems get solved. You will begin to do a few collections here and there to take care of the, to take care of the babies uh medical needs and stuff like that. So there are a few cases I’ve gone over there. And the problems were much more solved. Uh they they improved. The babies improved. Yeah and their survival rate also improved. Now some are doing very well, you know.

I: Ok. Do you feel like there’s any cultural barriers to mothers following the instructions?

P: Yeah. I think so. A lot. A lot. That is what I stated in the um sometimes you’ve got to go down to the homes and then see where they are staying and then tackle the problem from the root. But as I told you, financial constraints will not sometimes permit us to go there. How many times can I follow all these mothers with my meager salary? It’s not possible. So there are a few, we sacrifice. I and my colleague we sacrifice, we go there. But most of them we can’t. Yeah. And the hospital is not ready to foot those bills in because of the same financial constraints. So we lose touch, you know. Sometimes before you see them, maybe they come, they’re so sick. They come and die right there but they they are too poor. And it’s so sad. The mother has suffered so much and the baby through a narrow escape made it through through the efforts. So when we see them die, we really weep. Sometimes we weep. It’s so painful.

I: Yeah.

P: Because um due to one or two constraints the baby had to die. It’s so painful. Our hands are tied. You know, you can’t go beyond certain lines. That is why I keep on saying, what is this study going to really offer? Maybe it’s going to give NICU a a [inaudible-20:54], a [inaudible-20:55] or something. We can do much more to see our babies doing well because the passion is there. You want to see the babies. Sometimes they come so bad and you think this baby is going to die and then we we we team up. We have a, you know NICU, all pediatric eh workers, we are passionate. We add passion to the work. Unlike the older eh lots. But when it comes to babies and children, anybody that works in the baby suite or in the children, we are a lot of bit passionate. The doctors and the nurses. All of us. Sometimes we even fight when we want to get something done. The doctor will fight the nurse and the nurse will fight, ?when I come I’m annoyed? but I really don’t joke, you know. When I want to see a baby do well, when I finish you know, we are fine. We are friends back but when the technical to be done, we are all passionate. So when we struggle to see the baby through and when we see the baby come to die because they are constrained by finances, it is so painful! We have HIV mothers who cannot afford the feed, you know. And then we need to give them feed. We should be able to keep these babies on. And then the mother gets home, cannot afford the feed, so the mother begin to mix. Sometimes even they go for bigger formulas, which is not the baby’s level. The baby comes to die with diarrhea. It’s not their fault. When the baby was living in the NICU, so fine. Putting on the weight, the mother is zealous. There is no financial support.

I: Mhmm

P: Mhmm, no financial support. And then we we lose the battle with them because we can’t also follow them up, you know. So these these kind of constraints. They come and baby’s dead. The baby’s dead just like that (mumbles off).

I: Yeah. That sounds painful. So you said like the thing that is needed to increase babies living is more resources here,

P: Exactly!

I: more money, well more financial support

P: Exactly!

I: or at least from here like being able to fund whatever the mothers need.

P: Exactly. When

I: Is there anything else? Well, well you can say what you wanted to say.

P: Yeah, as you’re saying, to to be able to support mothers who are really in need, we can identify them. Some are really in need. They really need help, you know. And it’s a majority of them, you know. A majority of them really, some are in the middle, you know, once in a while they will need a [inaudible-23:36] here and there. And then the most of them really need anything. This region, teenage pregnancy is really high. The whole Ghana, the top, Central region, teenage pregnancy. They don’t have husbands. They’ve gotten pregnant. You know, you see the babies, we need the babies to go nice. We need them to experience. The mother don’t even have food, proper food, more balanced diet to eat to get the eh breastmilk in a good shape with a good nutritional standard to give to the baby. And then they come in a very bad state. You know, so as you saying, as you you you were trying to eh paraphrase, that is what I mean. We need resources in NICU. Both financially and then facility-wise. You know, to be able to really eh curtail some of the things that you need. Sometimes you’re aware that if they were there, most babies would have survived. Most of them because we didn’t add constraints now. Most eh eh eh a number of them do make it but what what is sad is they go and come back and come and die when we need them to go. Because we can no longer continue to support, continue to follow-up, continue to back them, you know so they go and come. Some will not even come. They die and they will bury them so you meet them in town, and they tell you, “My baby died.” “Why didn’t you come?” “I didn’t have money to pick transport to come. The baby just died maybe after a week or two.” Oh, so sad.

I: So besides the facilities and the financial constraints is there anything else you feel like is needed to…

P: Counseling. Counseling.

I: Ok. More counseling.

P: Exactly. Counseling. You know, counseling. I think some, most of the staffs should be trained in counseling. Because most of them, really sometimes don’t even know how to really counsel their mothers. You know, and then the hospital is not ready to put money in that aspect. But I think that aspect is very important. You know, when they the properlys are counseled even as to, let’s say in our setting once the mother give birth to a preterm. You say, “Oh I gave birth to a preterm sometime. These ones they don’t survive. That is dead. I deal with it. They don’t survive.” But when they are counseled that preterms can make it, they can even become better. You know they give birth and then they want to bring them for us to help. Sometimes they will deliver, by the time they get here, the baby’s so cold, you know. Cold has been cold for a and then the babies just die, you know. And then sometimes they think uh the babies that come with certain abnormalities. Maybe eh syndactyly or polydactyly or something. They think they are from Satan because they think they’re no good. So sometimes they leave them to die. So they wait until the baby’s about to ?cock? off. Then they rush the baby here and then you know. So traditional beliefs and then lack of knowledge, ignorance, also continue to ?do the death to yeah African in many settings?.

I: So I’m sure you feel like there needs to be more antenatal counseling and counseling after, but which do you feel is the one that there needs to be more counseling right now? Like more antenatal or more postnatal counseling?

P: Both.

I: Both? Ok.

P: Both. Both. And even before. Pre-pre-prenatal. Even before they get pregnant. You know. Uh uh young ladies need to be informed as to what to expect, you know. So that they get prepared because some just enter, they start giving birth or they just uh start involving themselves in uh sexual things not knowing they can get pregnant and then the the outcome of pregnancy. You can give birth to a baby with sex. And they are not prepared! They are not prepared whatsoever. So the term just hits them and then they are they are they are lost, you know. So even before uh uh uh antenatal, people need to get information. Yeah. They need to get information.

I: Ok. Have you ever received formal training on how to handle these cases of babies that survive when you thought they would have died?

(long pause and noise disruption)

I: Ok. So yeah, have you ever received formal training on how to handle these cases of babies that survive when you thought they would have died?

P: Formal training on how to handle those babies?

I: Mmhmm

P: Um. Formal training? Well I would say maybe yes. I mean, I was trained by um a non-governmental [inaudible-28:57]. I don’t know whether you’ve heard of [inaudible-28:59], good. It’s a US-based non-governmental that are getting uh trained for um baby baby resuscitation. So I was trained, given my equipment. They trained me, they gave me the equipment on how to really uh resuscitate babies and I was trained at the facility too. So, the trainer of trainers. So I trained people how to do um um neonatal resuscitation and then I trained facilitators to be able to train other people, yes. Um that aside um I wouldn’t say there has been any other training uh as to as to um concerning how to handle maybe uh special babies. But what we do is we have in-service training that goes on in our department. Every Tuesday, we have presentations. You know (mumbles) all day, all day eh eh conditions. Neonatal conditions from jaundice to um you can think of all of them. You know, every Tuesday there are presentations so uh through the presentations, you pick the sense and then the long you stay on the ward with babies, the more you get experience. Yeah. I am not a pediatric nurse. I have not been trained as a pediatric nurse, but from my, I was picked for my passion for babies. You know I did very well when I was a junior staff manning the pediatric ward. That one, even that, but even then it wasn’t the NICU. So I was recommended to handle the uh the NICU and then since then, I’ve handled the NICU. Uh I’m very good at monitoring. Yeah. Very good in uh assessing babies. You know, I’ve seen babies or I’ve seen kids or I’ve seen my patients and then from afar I can tell you maybe this patient. You know, so I think that is my gift so that is why I was recommended to run NICU. And then, so far so good. So the more you handle the babies, you get experience. But I’m not a pediatric nurse. Um but I have been trained as a trainer of trainer for neonatal resuscitation, yes. And then I’m also a um a preceptor, you know. And then I’m a I’m a HIV/AIDS counselor. I’ve also been trained as a trainer of trainers HIV/AIDS counselor. And then a number of the quality improvement teams, you know. Yeah.

I: Ok. So you’ve had a lot of training. That at least touched on how to take care of the babies.

P: Yeah. Yeah.

I: Do you think there should be more training on how to handle these kind of babies that survive when you thought that they were going to die? Like there needs to be more training for that?

P: I think so. I think so. I think so.

I: What kind of training?

P: Uh what kind of training? Um I think practical training or hmm very, very um um welcomed. It will go a long way you know when. What I was even thinking of, that there would be exchange programs. Aside the training in resuscitation, uh trying to give up the knowledge of resuscitation because some people you give them the training today, the next day you go and see them, they are doing something wrong. Apart from that, I think there should also be exchange programs. You know, if the nurses here could be eh eh eh could have that opportunity to see how the care, the care for babies elsewhere. Elsewhere means outside Ghana. You know, maybe two weeks, three weeks, stay in maybe uh maybe uh where April works. Michigan or something. To see how they they do their ?evals? in ?concern of? neonates. You know you come and affects the way you see things. You begin to run around and you see the, you you you that kind of encounter will really change your way of good. So we’ve had a couple of trainings and sometimes they say that’s normal. It’s normal. Even when they say we’re going to have a training on [inaudible-33:56] we’ve had it and had it. You know, or when they they they they get that that kind of encounter, I think it will change a lot of things. Because I had the encounter of working with this white who trained me. You know they they they stayed with us for about a month. And when the babies come, we call the babies themselves and they begin to work with you, you know. And then when you “ah!” they will tell you, “No, next time you go this way.” And there were times, you know, I was shocked there were times I also had to correct them ah. They were a wow! It’s good. It worked! And it boost my morale morale, you know. So anytime I really want to do something to see the babies and they do well. You know, so working with them maybe has affected me positively. Changing the way I see things. Changing the way I work. Simply my my my my attitude. I mean. And they believe in going the extra mile. You know, if there’s something you can do, if there’s something you can do, they always ask that question. So you sit down “is there something I can do? The mother doesn’t have the money blah blah blah blah. We are now at this level. Is there something else we can do to still help this baby?” So they will always put you in the thinking of want to be able to help. Yes. Asking the level it can go. So I think an exchange program will really go a long way to help Ghanaian nurses truly care for their patients with, I mean, especially the babies. You know because uh uh uh infant mortality, you know what is making our infant mortality go up if the units are there.

I: Mmhmm. Yeah.

P: It is the trunk of it, yes, it is the trunk of it. So if you get that chance to have that exchange program, just think how we could handle the the the cases as of when they come. And think if we really do [inaudible-35:56]. We can really improve [inaudible-36:04].

I: Well that sounds like a really good idea. What do you believe is the most important thing in general to understand in order to handle these cases of babies that survived when they looked like they were going to die?

P: Come again?

I: Like what do you think in general is like the most important thing for, like for a nurse to understand when handling a case of a baby that survives when they look like they were going to die?

P: Whoever is handling the baby should be knowledgeable. Very knowledgeable. You should know what to do at what point in time. And then the facilities should be there. That’s all.

I: Ok. What do you think is the most important thing for mothers to understand when you’re discharging their baby that almost die?

P: Mmm. Um the most important thing here is mothers who understand the condition of their babies. If you really know why their babies were brought here, the level at which their babies are being discharged, um what those babies need at the point in time after they are going home. You know and um um when they should come. You know for check-ups. Yes. These are the things the mothers should, should really understand. Yes and get it. Yea.

I: Are you familiar with the term near miss?

P: Neo miss?

I: Near miss.

P: New miss?

I: Near miss.

P: Neo miss?

I: Near miss.

P: Near miss?

I: Yeah.

P: No. I’m not familiar with it.

I: So near miss is kind of what we’ve been talking about. When the baby looked like they were going to die but they make it for whatever reason. Do you think having the distinction of knowing the baby had a near miss is useful for you as a health care worker?

P: Yeah. Having an idea that the baby was near miss is useful for me. I think so. I think it will inform me as to how to take care of another baby when the when the time comes. You know, uh if a baby was near miss and maybe I put in one or two interventions and the baby made it, uh, it it it boost my morale and then it gives me, it informs me the next time baby, if another baby comes in the same condition or even worse, maybe putting in that intervention can go a long way to help the baby. Yeah. So it it’s really important to me. It’s really important.

I: Ok. So I mean, the, you kind of touched on this.

P: It really makes me happy. You know uh it makes me feel achieved. I I I I’ve made a mark. I’ve been able to achieve. You know. Yeah. So babies in that category, near miss, anytime I see them I feel so happy. Just so happy. You know, I’ve been able to put a smile on the mother’s face. And then what makes me more happy? When I see the baby going with very minimal complications. Oh the joy. It’s really great. Yeah.

I: What do you think in-increases the chance that that baby will grow up with very minimal complications?

P: What increases the chance? Uhm as I said it boils down to the same issue. Facilities, and uh the the state in which the baby came. And the the the interventions we were able to put in promptly. You know, how swiftly we are able to assess the baby, know the level of that baby, know what the baby need at that particular time and then the interventions we’re able to put in. Yes, the interventions we were able to put in (mumbles off).

I: So if you knew a baby was classified as having a near miss do you think it would change how you manage that baby after the near miss?

P: Um I think so. It would change it. As I told you, as I said earlier on, those babies, when they are discharged, you know we we we really put in a lot of counseling. And even before they are discharged, we the the their monitoring is is special. You know, I have the baby now. I have one baby at the pediatric ward. The baby came, we thought the baby had um atresia. Eh we realized that it wasn’t atresia. We thought the baby had stenosis. We realized that it wasn’t stenosis. We thought the baby had maybe some kind of um a nutritional problem, nutritional intolerance. So and then we realized that it wasn’t too. So what was causing this baby to co-to to to really not for weeks, feed. You know this baby was born with some [inaudible-41:29] nothing would stay in there. So the baby was on IV fluids, the baby was maintained-o but going skinny and skinny and skinny, you know. So that baby was near miss. You know uh any day I get to the ward before even I put my file, I ask, “Is baby Cakes okay?” Say, “Ok thanks.” Then I’m making sign of cross. Thank god. You know so it continued. You know, uh, I don’t know but we didn’t do anything special. Apart from if I would say we didn’t do anything special maybe physically but uh I would say I did something special spiritually. Because at that point in time, I had to pray for the baby. I’m a Pentecostal. Um my belief tells me that there is no sickness without the spiritual background. So at that point in time, so now they say that baby is for me. Today the baby we lost, ?its the moments that I didn’t pray for them because I have prayed that that baby had to go to God?. So at a point in time, I had to go. I really took dextrose. Uh 10% dextrose. And then I had to pray, that I turn this dextrose into the blood of Jesus. I really don’t care whether you believe it or not.

I: Oh! (makes gesture for her to continue)

P: Good. I turned it into the blood of Jesus because my Bible tells me the blood of Jesus heals. ‘In his blood we are healed.’ So I give this blood to this baby because the blood of Jesus as a communion. And I want to declare that you must get well because we’ve done everything. We’ve exhausted everything.

I: Mhmm

P: We’ve exhausted the the antibiotics. Everything that we thought could be the problem was ruled out. So I gave that thing to the baby and the baby took it. And I gave 10 mils (/mL/) and the baby dropped out about a mil or 2. I said, ‘Let’s give again.’ So we gave again after two hours. It stayed so they said let’s start with breast milk. So they gave. And then during the night the baby the baby vomited about 2 or 3. Unlike previously, then immediately it gets ill. We see the baby just vomiting. We were even afraid the baby was going to aspirate and die. You know, because the way the vomiting comes, projectile vomiting. So we gave we gave we gave the baby ?continued vomiting?. We continued ?to be?. So I think it’s spiritual. And eh I think it was a near miss. But at the point and time, you have to combine spiritual and physical. So as I’m talking now, the baby’s at the pedics. Because now he’s about uh 28 days and he cannot continue to stay in the NICU. So the baby is now okay. Later on the doctors said they suspected meningitis too so they had to put the baby on [inaudible drug name-44:47] again for 14 days. So we are waiting for the baby to finish with this [inaudible-44:52]. Not because of the vomiting but because of meningitis. Another diagnosis where so, you know. These are some of the things, uh huh. Uh at that point in time, I realized that I realized that there’s nothing I could do than to. And then I had the consent of the mother. The mother, too, is a Christian and believes, you know. And believes, let’s let’s do anything. You know, let’s combine God, physical, and spiritual. And believe there’s something wrong. So that is how the baby has survived.

I: Ok. What challenges do you think that babies who experienced a near miss will face as they get older?

P: What challenges? Challenges. Babies who experienced near miss will face as they get older. It depends on the type of condition. This baby for instance. I don’t think the baby’s going to face any challenge because we didn’t understand why the baby was vomiting. Now that everything is fine, everything was ruled out. Um the baby is fine. Uhm the meningitis was also picked up, was suspected. Because when we did the the LP, uh CS, there was nothing I should be [inaudible-26:29] but the clinical find so they wanted to treat. Oh this baby like this. I really can’t think of any challenge, you know. But other babies maybe with a severe asphyxiated kernicterus, you know, they might end up with palsies. They might end up with speech problems. They might end up with sight problems, depending on which part of the brain this, they got, uh that was affected. You know, and even babies that come here with tetanus or meningitis, if it was really meningitis, they’ll have hearing problems, speech problems, and all the other complications. So these challenges could stay in in in, could show up later in life depending on the type of uh uh diseases or uh or the type of condition the baby got. How how how well it was managed.

I: Ok. Do you ever, have you ever discussed these, a case of near miss with your supervisor or coworker?

P: Yeah. Almost every day.

I: And so when you discuss what is usually the point of discussing it. What do you get out of the discussion?

P: Well, my interest of discussing it with them is for them to improve the working environment. Get things working. Maybe the baby came, we didn’t have certain equipment working but the baby survived. You know, so maybe I go like “This baby would have died maybe if it weren’t for the intervention of this and this and this and we didn’t have this, we didn’t have that.” So just to also encourage them to really sit up and try to put things in place so that the work could go on. Yes. Um that aside other, for them to see the hard work we are doing. The the uh they will also push it up. For them to really see the essence to provide certain things, you know. Because sometimes we think that, you know, not we think. I personally think some of the facilities we need here could have been uh uh gotten if those up there um rise up to the occasion. When I say rise up, what I mean is you know uh there are people who are ready to help. Just tell them reach out to the [inaudible-49:18] you just need the go ahead from the big people. The go ahead, do media invitation or a press conference. Tell them we need this, this this. And you have philanthropists in the society who will be ready to say, “I want to buy one woman,” or “I want to give you an incubator,” or “I want to buy [inaudible-49:38]” There are people who are ready to do that. So we don’t know why they don’t want to give them that go ahead. To really go on and do it. You know, when I came—I’ve been here for just a year—you know, I went up there and suggested some few things because when I came here, here I’m not the boss of NICU. I came to meet before. I came from [inaudible-50:00], I was the boss there. You know, so I can go straight to them to uh huh. And the boss there [inaudible-50:09] gives me that air. Because he learned that I was working with passion. So he goes like, “Sister whatever you think will be useful, just go ahead. Just do it. You want us to write to people? Just do it. You want us…” Sometimes I write we need [inaudible-50:26]. We need support. Ok let’s support some thing. You know, that’s all. Here it’s not like that. Support is not forthcoming as it is. And then lots of people are ready to go to the [inaudible-50:40]. But the backing is not there, you know. So if I discuss near miss with my supervisor, I will speak to them to push the fence up. And then let them see the need for us to get these facilities here. It will help us get a lot of near miss, you know babies who are about to die and then through some family intervention, they make it, you know. I’m expecting them to push these things. And I’m expecting those up there to also listen to these thoughts and then ginger them to do more. Go the extra mile as we have really struggled. But sometimes, you know, you have [inaudible-51:27] you hear their response concerning this near miss. You know, it seems it doesn’t matter to them. You know, and there was one thing in uh, I don’t know whether to say in Ghana or not in Ghana. New things could send babies are not taken serious.

I: Why not?

P: I don’t know. I don’t know. You know this big hospital was built with no NICU in it. It was built by whites. Sometimes I even also blame them. Because where they are coming from, if you want to get people who are good, who think better, who work better. To start from when they were born. So when you are putting up this. Why, why no NICU in the plan? There’s nothing like baby care, NICU. No. And this is not the first one. No. Where I’m coming from, there was nothing like NICU. The people built this facility are the same people who built the one uh at the [inaudible-52:29, mentions a location]. There was no NICU in the plan. That, so all the NICUs have come down here from the pediatric ward. But I think there should be NICU in the plan. So things concerning babies or kids, well most of them, it’s the last thing they think of. But I have realized, it’s even the most important thing. You know, that is the last thing they think of. The last thing they think of. Yeah. It’s something I have realized. The last thing they think of. Almost all the NICUs were carved out. Even \_\_\_\_\_ NICU was not in the picture because literally NICU was was, you know, it’s so sad. Any time I think about that thing, because I’m very passionate with babies, you know, very very. And with kids. You know, I sometimes even fight when I’m in town ‘cause I see people mistreating kids. I will stop my car and go and fight on the kids’ behalf. And then the mothers will be like “oh, we are sorry. They will not do that again.” Why? Why do you keep the kid this way? So we have learned everything about children, you know. It’s it’s it’s, you know, I I I heard that there’s even a policy for this. You know what it said? Everything about the baby is very expensive so if they if they have 1 million then they can save about 10 men or 10 women. That would make 1 million, who has to save one baby. The policy workers will not put that 1 million in the saving of one baby. While there are 10, you know what I’m saying to you? While there are 10 men or 10 adults to be saved. So the baby side we get nothing. And the money they put in something a policy, that can save uh maybe uh maybe 20 adults. In a policy that can save childrens. If the policy will save just one baby or two babies, it is not profitable and that is sad.

I: That is sad.

P: That is sad. All because ?its carved out?. It’s too painful. It is so sad. You see, it is not in the picture. Nobody was thinking about babies, you know. So we continue to have this thing. Now it has improved as compared to formally. It has improved but it still does, still more to be done. You know, that is why the pediatric doctors and nurses, we normally fight. You know, because sometimes we are neglected. You’ve got to really talk, fight before we get things done. Babies are not [inaudible-55:22]. One baby can take about three, four syringes of oxygen before the baby gets well. As maybe an adult could take personal [inaudible-55:32]. So why do we spend? Do do do you see the idea now? The thinking? It’s it’s it’s so bad. It’s so bad.

I: What do you think needs to be done to change that ideology?

P: (pause)

I: It’s okay if you don’t know, cause I don’t know

P: (laughs). Oh well well well well well from the way it goes, I don’t think they should have believe in that, I don’t. It’s just an emotional [inaudible-56:06]. I don’t think they should have been. So sometimes I wonder why cant [inaudible-56:16], think that way. You got it, yes, you got it (referring to interviewer). Sometimes I think ‘Why are they think that way? Why they build the whole hospital without NICU?’ We are the people of emphasis, emphasis of maternal and child and child starts from birth. So how can you think about building a whole hospital with NICU, without NICU in the plan? So when I think, I been thinking of how they think like that. Actually I don’t know about it. Why they think like that? I don’t know about it but how it can be changed. Maybe maybe they should be informed. Maybe they don’t know. Maybe. Maybe they are aware but they think of something. They think it is wasteful to put our meager resources in that aspect as to thinking maybe their rate of survival or their change of living eh cannot be guaranteed so why do you put this resources. Maybe that is how they are thinking. How most of them will not survive. But it’s high time we think that, we change that idea. ‘Cause most of them survive. And they do so well, yes. Every day has told me [inaudible- 57:41]. That most of them will not survive. Why do we put resources in there. As we have to prepare for malaria, no let’s put the money in the mosquito, set aside for mosquito net. Why do we put the money when for us we don’t know their rate of survival. Their chances of living. That is how they are thinking. Maybe.

I: Maybe.

P: Maybe. Maybe.

I: Ok. Um do you have any other comments about near miss that you think is important for us doing the study to understand? (pause) That you haven’t already talked about.

P: Hmmm. Uhhm not really. Maybe I would rather emphasize, I would rather emphasize on the exchange program. It’s something dear to my heart. Because I have seen people working, other professionals. Doctors, anesthetists, nurses working on a tiny baby, just to make the baby survive. You know, and they wish and run and scream that the baby makes it. A lot of passion, we need it. You know, and I think people can get, when they get that kind of income. You know, and then they will be aware that we’ll be able to get a lot of this near miss when they put in that extra, they get that extra passion, they go that extra mile to really do everything to see babies uhm make it. Um besides that, I’ve talked about the facilities. The [inaudible-59:36]. Uh if we can get, if we can get the um a supporting uh go-between over there who will support [inaudible-59:48] even the NICU. Who will support NICUs. You know, who will make sure that we have NICUs running and that we have uh eh eh eh enclosed set within the NICUs to do follow-ups. It can work magic. When the baby starts discharge we do [inaudible-1:00:12] and we support them. We support them, it will work. It will really work. After the near miss the baby is continue to survive. ‘Cause, as I’ve said, the near, we have the near misses who come back and come die. And that is what, that is what, I mean, pains us so much. Near misses that it really demoralizes us. Yeah. So if we can get that kind of backing, that kind of support, you know. A group that is dedicated to see the NICU running. Understand that when the babies are discharged we continue to see them doing well and for a certain level whether they are ok. And, yes. And uh, we have people who are ready to do that. As I said, I’m doing it but but I I have a limit. I I I eh sometimes you you you have the passion to do this, you don’t have the means. Yes. You don’t have the means. \_\_\_\_\_\_\_\_\_\_\_\_\_\_ You have a driver that can be paid from this end or whoever, if the \_\_\_\_\_\_\_\_ hospital is going to say that’s enough. A driver who will be paid. We have nurses who will bring this in addition to their responsibilities who will be following those babies up. Not by their own resources but we can be supported to do this. There are people who have the passion to do this. There are nurses and doctors who are ready to do that. Yes. Yes. And even that’s can serve as, it can serve as an education uh uh uh an education or it can serve as um an information through the populace to disabuse the minds from this uh family belief that these babies don’t make it. Because when we get the babies doing well and then they will begin to see those testimonies. These babies was as tiny as this. And the baby has done well. The baby’s doing well in school. The child is doing well in school. He is growing. He’s just, you know. And then people get to disabuse the minds of everybody including policy makers. This will change. Yes. When we get the backing. This will change. You know, this in my mind, the combinations (mumbles off)

I: Alright, well thank you again for taking the time for answering our questions. There’s a lot of good…I feel like I’m hearing stuff I’ve never really heard before. Uh we hope your answers help us understand more about why babies that seemed as though they would have died live instead so we can increase the number that life instead. I mean, for me, this project, I’m really hoping to figure out ways to help more babies live and then also we’re thinking about, you know, it’s like, you know, neonatal mortality is high and so it’s almost like we’re looking at these babies that almost died but made it to see like how can we increase babies that make it. Also make sure they still make it ‘cause the rate of babies that die before five is still kind of high. So we’re tryna figure out those kinds of things. Um please let me know if you have any questions. I’ll make sure to ask April about how this should directly help this hospital. But any other questions?

P: I think I asked my question from the beginning of the interview.

I: Yeah. Ok.

P: The essence of whether the NICU is really going to receive some support. If I had this type of information. Apart from sharing it with authorities

I: Yeah.

P: Whether we are going to see physical support.

I: Like direct…?

P: Good. Whether it’s really going to reflect on the ward. That was my question.

I: Ok. Well I’ll ask her that too and you can ask her if you see her. But if you have future questions, you can reach me through her. Alright, thank you and thank you for sticking around. I’m sorry (cuts out).

END OF INTERVIEW