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RESEARCH ARTICLE

“My baby is fine, no need for more clinic visits.” Facilitators and barriers for utilisation of follow-up services for children born preterm in low-resource setting: Parents’ perceptions

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Abstract

Objectives: We sought to understand the facilitators and barriers impacting utilisation of follow-up services for children born preterm as perceived by parents in a low-resource setting.

Methods: We conducted a qualitative study at Mulago Hospital, Uganda, with parents of children born preterm and aged 22–38 months at the time of the study. We collected data using five in-depth interviews and four focus group discussions. Data were analysed using thematic analysis informed by the social-ecological model.

Results: Ten subthemes emerged that could be grouped into three main themes: (1) *Individual*: parents’ knowledge, parenting skills, perception of follow-up and infant’s condition; (2) *Relationship*: support for the mother and information sharing; (3) *Institution*: facility setup, cost of care, available personnel and distance from the facility. Parents of preterm infants perceived receiving timely information, better understanding of prematurity and its complications, support from spouses, availability of free services and encouragement from health workers as facilitators for utilisation of follow-up services. Limited male involvement, parents’ negative perception of follow-up, stable condition of infant, health facility challenges especially congestion at the hospital, distance and care costs were key barriers.

Conclusion: An interplay of facilitators and barriers at individual, interpersonal and health system levels encourage or deter parents from taking their preterm children for follow-up services. Improving utilisation of services will require educating parents on the importance of follow-up even when children are not sick, eliciting maternal support from spouses and peers and addressing health system gaps that make follow-up unattractive and costly.

KEYWORDS

barriers, facilitators, follow-up, preterm, qualitative study, Uganda

INTRODUCTION

More than one in 10 babies are born preterm, accounting for 15 million births per year globally [1, 2]. Over 60% of preterm births occur in sub-Saharan Africa and Asia [2]. Uganda has a relatively high preterm birth rate of 14%

[3, 4]. Prematurity and its related complications are the leading cause of morbidity and mortality in the neonatal period [2]. Efforts towards improving outcome of preterm babies need to include high-quality in-patient and follow-up care after discharge [5]. WHO recommends early and frequent follow-up visits for at-risk infants (<37 weeks and low birth weight < 2500 g) either at the facility or by skilled providers in the community [6]. Suggested schemes are two

Sustainable Development Goal: Good Health and Wellbeing.

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visits per week until 37 weeks of post-menstrual age (PMA) and one visit per week after 37 weeks of PMA to 40 weeks or when infants weigh >2500 g [6]. Adherence to follow-up is affected by multiple factors such as availability of resources, distance to the facility and support for the mother [7, 8].

There is a wide disparity in outcome of premature babies depending on where they are born. Limited resources, skilled personnel and a high disease burden contribute to poor outcome in low-resource settings [9]. Survivors are at particular risk of life-long health problems including growth, nutrition, and neurodevelopment deficits [10, 11]. These pose a challenge not only to the health of the child, but also to their families and society, and cause loss of human potential. Follow-up programs are important for early detection and intervention in case of adverse conditions to improve outcome [12].

Providing follow-up services have cost implications and constraints on available public resources in some low- and middle-income countries [13–15]. There are no national or facility-based data about follow-up practices in Uganda. Despite the challenges, it is generally assumed that follow-up could increase the proportion of survivors of prematurity [16]. In our setting, early discharge due to limited bed capacity and social aspects is common. This increases the risk of morbidity and mortality of the most vulnerable infants especially in the first few months of life, requiring frequent follow-up [17–19]. In many public facilities, follow-up for preterm infants takes place in the general paediatric or outpatient department, rather than through designated clinical services. At Mulago Hospital, a special follow-up clinical service for preterm and low birth weight infants is run twice every week within the department of Paediatrics. Preliminary data obtained from the clinical records for 2016 showed a low utilisation of the follow-up services with more than 70% of attendees lost before 6 months of life (unpublished data from the 2016 Health Management Information System of Mulago Hospital (HMIS) reference form 105). We examined parents' perceptions concerning facilitators and barriers to utilisation of follow-up services for children born preterm at Mulago Hospital, Uganda.

METHODS

Study design, setting and population

We conducted a qualitative study between November 2019 and February 2020 at Mulago National Referral Hospital. Mulago is the training institution for Makerere University College of Health Sciences and serves the urban and peri-urban population of Kampala, the capital city of Uganda and surrounding districts.

Approximately 32,000 babies were born at the hospital in 2017, and about 5000 (both in-born and out-born) were admitted to the neonatal unit (HMIS 2017). Of these, 48% were preterm defined as <37 weeks gestation age and/or with low birth weight (LBW) <2500 g. Often the exact

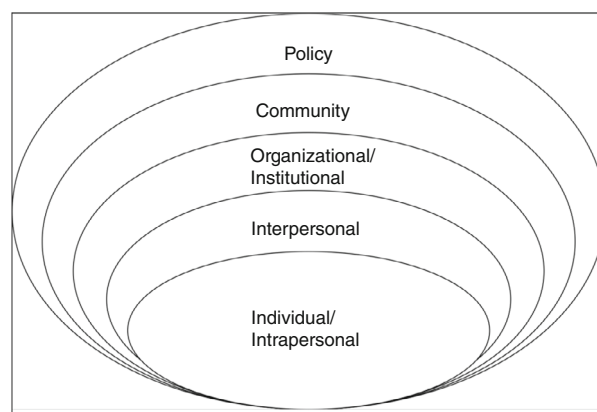


FIGURE 1 Showing the Socio-ecological model, adapted from McLeroy, Bibeau, Steckler, and Glanz (1988).

gestational age is unknown. The unit has 38 cots, 22 incubators, and six adult beds for Kangaroo mother care (KMC) but often admits thrice its capacity. Due to the many admissions and limited bed capacity, early discharge for babies is inevitable. Discharge at Mulago Hospital is not based on WHO-recommended weight gained of ≥ 1800 g. Babies are discharged when considered stable, defined as off oxygen, tolerating at least 180 mL/kg/day of expressed breastmilk, normal body temperature in the cot or KMC and gaining weight [18, 19]. The majority of the babies are discharged earlier than they would in a high-income setting, making follow-up extra important. Initial follow-up at the clinic is every 2 weeks until the baby weighs 2500 g; thereafter every 2 months for the first 2 months of life and then every 3 months until the age of 18 months PMA (modified from WHO guideline) [6]. On average 50 children are seen in the follow-up clinic per week.

Services offered at the preterm follow-up clinic are growth monitoring, counselling on infant feeding, supplement (multivitamins) refill and readmission of unwell infants. The clinic is run by one paediatrician, a resident doctor and a general nurse. All professional services are free of charge. Parents pay for their transport fare to and from the hospital, some investigations and medicines that may not be available at the clinic when needed.

Parents of children born preterm, aged 22–38 months at the time of the study were purposely selected from the clinic registry. Using the telephone number registered at the clinic, they were called and invited to participate in the study. Consent was obtained from all parents. Participating parents were able to communicate in Luganda (local language) or English.

We used in-depth interviews (IDIs) and focus group discussions (FGDs) with parents to investigate facilitators and barriers that impact utilisation of follow-up services for children born preterm. We draw on the socio-ecological model (SEM), a theory-based framework for understanding how the social determinants of health influence and maintain health and health-related issues (Figure 1) [20]. In the

current study, at individual level both infant's and parent's factors were considered.

Data collection methods

We conceptualised the parents' experiences of taking care of preterm infants and elicited the subthemes related to their experiences. Facilitators were those experiences that enabled the parents to utilise the follow-up services after discharge from hospital while the barriers hindered them.

For the focus group discussions mothers were divided in four groups each, with no more than 11 participants per group. During the discussion, participants were assigned numbers and their responses were recorded using numbers for confidentiality. Fathers of preterm infants participated in the in-depth (one-on-one) interviews. Both the in-depth interviews and FGDs were conducted within the hospital premises. The FGDs and interviews were conducted by a moderator and a transcriptionist, both trained in qualitative research but not employees of the hospital and fluent in both Luganda and English. A semi-structured guide with open-ended questions was used to conduct the interviews and discussions each lasted 30–60 min, they were audio recorded and transcribed. At the end of four FGDs and five in-depth interviews, no new information emerged regarding facilitators and barriers to utilisation of follow-up services for children born preterm.

Data analysis

Data were analysed manually using a thematic approach. Two of the authors (FN and JR) read the transcripts

independently several times to identify patterns. These were then compared and contrasted, after which meaningful content was condensed and assigned shorter codes to describe it. Subsequently, a codebook was developed to support this process. All FGD transcripts were then re-read while applying the codebook to ensure that all common subthemes regarding parents' experiences were identified. These could then be grouped under the themes 'individual level', 'relationship level' and 'institutional level'. Facilitators and barriers were identified based on the most expressed views by the parents and selected quotes were used to illustrate subthemes.

Ethical considerations

The study was approved by Makerere University School of Medicine Research and Ethics Committee (REC REF 2019-117) and the Uganda National Council of Science and Technology (REF: HS 2690). Administrative clearance was obtained from Mulago Hospital and written informed consent was obtained from the parents.

RESULTS

Characteristics of study participants

Thirty-nine mothers participated in the FGDs and five fathers participated in the in-depth interviews. Most of the mothers were aged between 26 and 30 years. More than half of the study participants had completed 1 year of follow-up at the pre-term clinic.

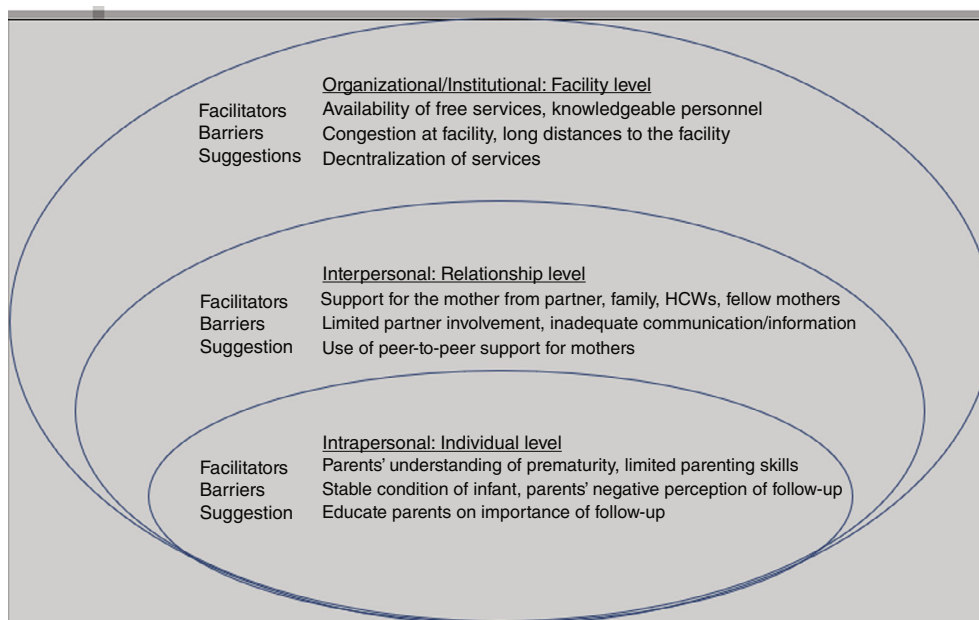


FIGURE 2 Emerging subthemes on facilitators and barriers impacting utilisation of follow-up care for children born preterm at Mulago Hospital.

Emerging subthemes for utilisation of follow-up care

The results were categorised as facilitators and barriers influencing follow-up of children born preterm, and suggestions given by the participants to improve follow-up. Subthemes were identified and organised at individual, relationship and facility levels based on the socio-ecological model (Figure 2).

Facilitators and barriers of utilisation of follow-up at the individual level: Parents' knowledge

Nearly all parents demonstrated understanding of what prematurity is and what its impact might be on the health of their babies. Such knowledge may contribute to parents' health-seeking practices after the birth of a preterm baby. Most parents knew that these children were born early; they could provide a definition of prematurity and describe their physical appearance. The parents were aware that these babies were more prone to problems shortly after birth and later in life than those born at term, as cited below.

It means a child was forced out of the womb or born before they made nine months in the womb.—FGD 4, Mom 3.

My twins, one was very small. Her size was equivalent to a small flask. She was extremely small. She had breathing complications. She could not feed well and generally her health was not good. Such reasons inspired us to make continuous follow up to know what could be wrong if any complication arose.—IDI, Dad 3.

They do not walk at the time when others born at nine months do even talking. Actually, most of their milestones happen later.—FDG 2, Mom 4.

Some respondents linked limited parental understanding of the problems that premature babies are likely to get as a barrier to utilisation of follow-up services. In this case, follow-up may not be considered important as one mother narrated another mother's experience.

My sister in-law had delivered a preterm and he had complications due to neglect. I was prompted to continue follow-up as I didn't want mine to be like that of my in-law who is mentally retarded now. I was always eager to hear from the health worker if there is anything wrong with my baby. FGD 3, Mom 4.

She called me informing me that her child had finally made 3 kgs. My child by that time was standing and doing everything a child should be doing at that stage. But hers was not even sitting

that is because her child was not followed up.—FGD 1, Mom 4.

Parenting skills

Parenting skills were perceived to influence utilisation of follow-up services. First time parents and those having a preterm baby for the first time had little or no parental skills. They depended on the health care workers (HCWs) to guide them on how to care for their preterm babies. They complied to the follow-up instructions given by the HCWs as cited below.

It is always good to bring the baby for follow-up; as for my wife, this was her first-child. She had no idea of what takes place during such challenging moments, so these follow-ups helped us to avoid making mistakes which could affect the baby.—IDI, Dad 5.

Infants' condition and parents' negative perception of follow-up

Some parents stated that the follow-up helped them to monitor their babies' growth. They wanted to know if their babies had gained weight or not when compared to other babies and that their babies did not have any health problem. This motivated them to regularly come for follow-up, as cited below:

The other advantage of bringing back these children is that it helps you to know if your child is making progress or not. When you see that other people's children have added weight, it gives you the determination to do more.—FGD 2, Mom 6.

Some parents did not perceive follow-up as necessary when their children had no serious health problems requiring medication. They stopped coming for follow-up because they thought that simply having their babies examined was not reason enough to bring them. To some this was perceived as a waste of time and money as stated below.

What made me stop bringing the child at five months is because my child was fine.—FGD 3, Mom 3.

The other issue is when these mothers come for follow-up, there is no medication given to the babies. The health worker just examines the baby so they feel it's a waste of time and makes them not to come back.—FGD 3, Mom 4.

Parents need to understand the importance of the follow-up and not link it to baby's health condition alone. They felt that this explanation should be done shortly after

birth of their preterm babies and not wait until discharge, as cited below.

For me I think counseling about the care including follow-up should start right from the place we deliver from. When the mothers are discharged and they hear about coming back to the clinic, they do not understand why they have to do so and they just decide not to come.—FDG 4, Mom 1.

Facilitators and barriers of utilisation of follow-up at the relationship level

After birth of a preterm baby, the participants expressed need of support for the mothers from their partners, other members of the family, fellow mothers, health workers, friends and neighbours. Their physical, emotional, and psychological well-being facilitated them to take good care of their babies:

In most cases when it is your first born and it is a preterm, it is so scaring. But me my experience was that when both parents are involved, you will always advise and support one another even remember when to take your baby for follow-up. If a woman is alone with the premature baby, she may dump it. So, men should be encouraged to support their wives to care for their baby.—IDI, Dad 1.

Whenever I came back, I would meet my friends with whom we had been in hospital and we would be happy and discuss about our children. The health worker would also give us guidance on how to feed these children and it would help us take better care of them.—FGD 2, Mom 6.

Mothers expected support from the health workers but some expressed their disappointment as this was not the case:

“What caused me to fear a lot was because the health workers never encouraged us. Some of us this was our first child and we needed a lot of support and guidance but we never had counselors to support us and tell us what to do.” FGD 4, Mom 4.

Limited partner support

Some mothers described lack of support, especially from their partners as a barrier to the utilisation of follow-up services. When the mothers had no permission from their husbands to bring the babies to the clinic, they could not do so:

For me the one (mother) I know, the husband refused her to bring the child for follow up, ...

but it's been two years since and their child doesn't sit, he just lies down.—FGD 2, Mom 3.

Inadequate communication and information sharing

The participants stated that the HCWs needed to explain to them the importance or reason for the follow-up and how long it should be as this would help them to comply. When they did not get the correct information, it was hard for them to know what to do:

The health workers need to explain to us why we have to bring the children for that long. They just tell us to come back and sometimes the child is fine so you don't see the need for the endless journeys to the hospital.—IDI, Dad 2.

For me I think the health workers who should decide for us the time frame for which we should bring these children. Personally, I just got tired of coming and stopped. I kept bringing the child until she made 10 kgs because they said that when a child makes 10kgs they discharge you but for us we were not discharged.—FGD 3, Mom 1.

The mothers suggested that the mothers who have experience of caring for a preterm baby would be good supporters for fellow mothers to explain to them how to care for their preterm babies:

I think they should get people who have gone through the same situation to be the ones to talk to us because people who don't have this same experience may not understand.—FGD 2, Mom 1.

Facilitators and barriers of utilisation of follow-up at the institutional level

The participants stated availability of services for preterm children facilitated utilisation of the services because the parents had confidence in the health system. Some parents explained that it was better for the babies to be followed up at the hospital where they were born because the HCWs knew what to do:

I went to a nearby clinic, they tried to find the baby's vein but failed. We came back to Mulago and found a nurse trained in premature babies and she found the vein immediately. The health workers here know what to do.— FGD 3, Mom 3.

The care from the health facility also motivates us. Whenever we come, the health workers examine these babies even if they do not

administer any treatment. It shows that they really care and love these babies.—IDI, Dad 2.

Majority of the parents brought their babies to the clinic following the instructions given to them by the HCWs. They felt the follow-up paid off because their babies did well when they complied to the advice from the health workers:

According to what I can see, we should follow the HCWs' advice and follow their instructions. As for me, the baby did not over disturb me because I always fulfilled the appointments and advice given by the HCW.—FGD 1, Mom 7.

Some parents were happy with the free services they received at the clinic. Not having to pay except for the transport fare to the hospital facilitated follow-up:

Most people think the children's clinic is expensive, but we are not paying anything here. So, mothers should be sensitized that the services at Mulago Hospital are free of charge. It is only the parent to get transport....—FGD 2, Mom 8.

Congestion at the neonatal unit

Congestion at the neonatal unit discouraged some parents from continuing the care for their babies after discharge. Some parents feared that the clinic was as congested as the neonatal unit and they would not get enough attention from the HCWs:

There is also an issue of congestion. We got to a point where the premature babies were very many. We were told that for every child who makes 1000 grams would be discharged to create room for new ones. When mothers are told to come back to the clinic, they think that the ordeal they went through in the neonatal unit is what they will go through again. They refuse to come back and opt to use traditional ways of covering the baby until they stabilize.—FGD 2, Mom 2.

Distance from the facility

Most parents explained that the nearer they stayed to the facility, the easier it was for them to come for follow-up and that when their homes were further away from the hospital it was hard. Relocation and lack of transport fare were some of the reasons cited by the participants as affecting the utilisation of the follow-up services.

At first we used to stay in Kawanda but we moved further so I couldn't be in position to keep bringing this child." FGD 3, Mom 7.

"In most times it's transport, most families lack money to come to the clinic". FGD 1, Mom 4.

Decentralisation of services was suggested by the participants to improve utilisation of follow-up for children born preterm. The parents thought it was good to have similar services in other parts of the country especially in the rural areas for more babies born preterm to be followed up:

"The services should be referred to rural areas of Kalisizo because my brother told me they have so many babies who are covered up in the village and they end up dying because they don't know what to do.—FGD 2, Mom 7.

DISCUSSION

We sought to explore the facilitators and barriers influencing utilisation of follow-up services for children born preterm at Mulago Hospital, Kampala. Our findings showed parents' understanding of preterm birth, understanding importance of follow-up, limited parenting skills, support for the mother and free services at the hospital facilitated utilisation of the follow-up clinical services. The key barriers were stable condition of the infant, parents' negative perception of follow-up, limited partner support, inadequate communication, long distance from home and congestion at the hospital. Our findings highlight that the different levels as part of the socio-ecological model may impact on care uptake for preterm infants, interact in a complex manner and possibly reinforce each other.

At the individual level, the parents' knowledge of prematurity and related health problems facilitated follow-up. The visits were presumed to contribute to the babies' well-being and progress. Similarly, limited parenting skills, especially among first-time parents and those having a preterm baby for the first time, may facilitate compliance with the instructions given by HCWs. These findings about the parents' behaviour may be explained by feelings of anxiety, fear and stress that most parents develop after the birth of a preterm, which has been documented in other studies [21, 22]. Dependence on HCWs' expertise to care for their infants may be needed by some parents for guidance [23].

An important finding from our study was that follow-up was not considered necessary when the infant was well. This may require further exploration but highlights the need for continuous education of parents on the importance of follow-up of preterm children even when they are well. Follow-up should not be related to illness but monitoring the infants' growth and development. The perception towards follow-up could be explained by beliefs held regarding health-seeking behaviour. The fact that some parents considered follow-up unnecessary for a child that was perceived to be in good health was similar to findings from Australia and Canada [24, 25].

At the relationship level, support available for the mother facilitated utilisation of follow-up. Most mothers expressed the importance of the support they received from their partners which they said should not be limited to finances but extend to physical, emotional and psychosocial support. This would subsequently lessen stressful emotions and lead to timely decision making for follow-up. Similarly, support from fellow mothers, friends, neighbours and other family members were valuable and this has been previously documented [21, 22, 26].

Some mothers highlighted lack of support from their partners as a key barrier to follow-up. Fathers as heads of families are socially and culturally expected to provide for their children. Paternal participation in preterm care and perceptions thereof has not been well documented. Stress and anxiety may be some of the reasons leading to limited presence of fathers in care of the preterm as previously documented [27]. Importantly, male involvement has been shown to have a positive impact on maternal, newborn, and child health [28, 29].

Second, inadequate information sharing and support from the HCWs were other barriers mentioned by the parents. They felt they were not well informed and supported by the HCWs and this subsequently led to the low utilisation of the follow-up services. The gap in communication highlighted by our study has been described in the literature to impact negatively on health practices at various levels of care [30–32]. Strategies to improve this challenge need to be devised. For instance, participants suggested working with mothers to encourage fellow mothers as a feasible method of improving communication and information sharing. Parent-to-parent support has been shown to hold important promise and is currently recommended by WHO as an element of the comprehensive family support program for preterm care [33].

At the institutional level, the participants highlighted the free services offered at the hospital-facilitated follow-up. Care of a preterm infant has been associated with high costs during and after hospital discharge [34]. Therefore, when parents did not have to incur an extra cost during follow-up it was unsurprisingly perceived as a facilitator of follow-up. Furthermore, availability of HCWs who knew how to take care of preterm children motivated parents to continue follow-up. This could be explained by the bad experiences at other facilities which prompted them to continue care at the initial hospital. This could also imply the trust and relationship developed during the admission of the baby supported continued care.

Congestion at the hospital was one of the barriers described in the current study. In a high-volume setting, gaps in service delivery could arise. When individual parents' needs are not adequately met, it is likely that they shun the facility. In Ethiopia, long waiting hours due to few and busy HCWs were shown to affect service delivery [35].

Proximity to the facility made it easy for the parents to bring their children for follow-up, but a long distance from

home hindered them. Relocation further from hospital implied a higher transport fare which some parents could not afford as documented elsewhere [36]. Furthermore, when specialised services are available in only a limited number of tertiary or private facilities in the country, follow-up is compromised [9]. The participants suggested decentralisation of these services beyond the national referral hospital to ease follow-up and reach more children born preterm. Availability and accessibility to specialised services, trained personnel and community follow-up programs are still limited in low-resource settings and need to be addressed urgently [9, 37].

Our findings are a contribution to the scarce literature on follow-up of children born preterm in resource-limited settings. It provides insights towards the implementation of programs and policy recommendations to improve the outcome of survivors of prematurity. The findings demonstrate an interplay of factors at individual, relationship, and facility levels on the utilisation of follow-up care. These vary from parent to parent and interventions need to have a multifaceted approach. The strategies towards improving utilisation of follow-up services should focus on:

1. Bridging the communication gap between the parents and HCWs: Timely information sharing on prematurity and ongoing health consequences may improve parents' understanding and care for their babies. Educate parents on importance of follow-up even when the baby has no obvious illness.
2. Increasing male involvement and strengthening the parent-to-parent support approach.
3. Extending specialised preterm care services beyond the referral hospital and urban settings to reach more at-risk infants.

A strength of this study is its use of a qualitative design involving parents with lived experiences of an existing program. Follow-up of children born preterm is an under-researched topic in our setting and our findings could contribute to policy making for their care. The fact that this study was conducted in one large referral centre can be seen as a limitation. Another limitation might be that we utilised a convenience sample. We only interviewed parents who came to the hospital with living infants, which might have caused bias. We recommend future research to involve different levels of care for children born preterm.

CONCLUSION

Our study revealed an interplay of facilitators and barriers at individual, relationship and institutional levels that encourage or deter parents from taking their preterm children for follow-up. Improving utilisation of services will require educating parents on the importance of follow-up even when children are not sick, eliciting maternal support from male

partners and addressing health system gaps that make follow-up unattractive and costly.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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