Scientific Research Publishing

Open Journal of Pediatrics, 2024, 14, 686-699
https://www.scirp.org/journal/ojped
ISSN Online: 2160-8776
ISSN Print: 2160-8741

Parent-Reported Reasons for Loss-to-Follow Up in Patients Hospitalized at the Neonatology Unit at Laquintinie

Eposse Ekoube Charlotte[1,2], Puepi Djike Yolande[3], Hassanatou Iyawa[1,2], Mandeng Ma Linwa Edgar[3], Epée Patricia[1], Mbonjo Bitsie Dora[1], Kedy Mangamba Koum Daniele-Christiane[1]

[1]Faculty of Medicine and Pharmaceutical Sciences, University of Douala, Douala, Cameroon
[2]Paediatric Unit, Douala Laquintinie Hospital, Douala, Cameroon
[3]Faculty of Sciences, University of Douala, Douala, Cameroon
Email: eekoubec@yahoo.fr, yolandep2000@yahoo.fr, hassanatouiyawa@gmail.com, fideliedora@yahoo.fr, dckedykoum@yahoo.fr

How to cite this paper: Charlotte, E.E., Yolande, P.D., Iyawa, H., Edgar, M.M.L., Patricia, E., Dora, M.B. and Daniele-Christiane, K.M.K. (2024) Parent-Reported Reasons for Loss-to-Follow Up in Patients Hospitalized at the Neonatology Unit at Laquintinie. *Open Journal of Pediatrics*, **14**, 686-699.
https://doi.org/10.4236/ojped.2024.144065

Received: April 28, 2024
Accepted: June 10, 2024
Published: June 13, 2024

Abstract

Introduction: Despite the known benefits of newborn follow-up clinics, attendance has historically been difficult. Infants with reported "follow-up difficulty" have a greater incidence of severe sensorimotor and cognitive deficits and poorer access to early intervention programs. Our objective was to determine the parent-reported reasons for loss-to-follow up in patients hospitalised at the neonatology unit of Laquintinie Hospital. **Methodology:** We carried out a cross-sectional study through phone interviews with parents/caregivers of patients hospitalised at Laquintinie over a 2-year period from 1st January 2021 to 31st December 2022. A non-standardised structured interview guide was used for data collection. Loss-to-follow up referred to absence to at least one visit as recorded in the neonatal follow-up chart. All necessary administrative and ethical considerations were duly respected. **Results:** Most neonates were born through vaginal delivery (n = 313, 69.45%). The neonates were admitted at a median gestational age of 33 weeks (Q1-Q3; 32 - 35) and the median duration of hospitalisation was 12 days (Q1 - Q3; 8 - 18). A total of 23 neonates had died at the time of interview giving a mortality rate of 5.1%. The three most reported reasons for loss-to-follow-up was lack of money (n = 310, 68.13%), assumption that follow-up had ended (n = 37, 8.13%), and newborn that died (n = 23, 5.1%). **Conclusion:** This study highlights the significant impact of financial constraints and absence of a robust follow-up system on poor uptake of neonatal follow-up post-discharge in resource limited settings like Cameroon. Our results serve as advocacy for na-

tional health insurance especially in neonates.

Keywords

Loss-to-Follow Up, Cameroon, Neonates

1. Introduction

Newborn follow-up clinics have known benefits, but historically, attendance has been challenging [1]. Infants who face difficulties in attending these clinics are more likely to experience severe sensorimotor and cognitive deficits, and they have limited access to early intervention programs [2] [3] [4]. Loss to follow-up is a significant problem in neonatology, particularly for very preterm infants, and it is associated with social hardships [5]. Parents of disabled children may also be less inclined to participate in research. Loss to follow-up can occur due to various factors, including medical, sociodemographic, and maternal variables. Some factors linked to loss to follow-up include older gestational age, African American race, maternal cigarette smoking, younger age of women, multiparity, foreign-born status, lack of breastfeeding, and residing in low-income neighbourhoods [2] [6] [7] [8]. While greater distance from the clinic or hospital has historically been linked to loss to neonatal follow-up, some reports suggest that social variables play a more significant role in clinic attendance [2] [7]. Mother's education and number of children are some maternal factors that have been associated with number of times attending follow-up. [9]. Additionally, children with greater medical complexity and longer hospital stays are more likely to attend clinics [10] [11] [12]. The role of financial reasons for loss to follow-up remains controversial as some authors have shown that insurance status, as a proxy for socioeconomic level, does not predict loss to follow-up [1] [13]. On the other hand, larger gestational age has previously been associated with loss to neonatal follow-up, as families may perceive these newborns as healthy and doubt the necessity for developmental follow-up, resulting in minimal attendance [1].

Studies have reported that the percentage of first-visit no-show varies between 10% - 30%, and sustained rates of loss to follow-up range from 10% - 70% on consecutive visits [4]. In the UK and Portugal, Piedvache *et al.* reported a 45.8% proportion of patients lost to follow-up, while in the USA, Swearingen reported a 62% proportion over a two-year follow-up period [1] [14]. Neonatal follow-up is crucial when transitioning from the hospital to the outpatient setting, especially for neonates hospitalized for critical illnesses [15] [16]. These follow-up clinics are essential for early detection of abnormalities, making necessary referrals to medical specialists, and providing parents with guidance to improve cognitive and motor outcomes throughout infancy, with lasting cognitive benefits into preschool [17] [18].

It is common for newborn survivors to be discharged quickly for social or familial reasons, even if they have very low body weights, as long as they can feed on breast milk or formula after receiving intensive care in the neonatal unit [19] [20]. However, there is no formal mechanism for follow-up after discharge in Cameroon, except for a vaccination clinic. As a result, high-risk newborns who are discharged from the neonatal unit may not be able to receive expert follow-up care. Some high-risk newborns may experience death, persistent health issues, or developmental delays after going home, although the exact numbers are unclear, thereby sometimes overestimating the real outcomes post-discharge [14]. It is crucial to study the reasons behind loss to follow-up to guide care, with a special focus on social reasons. Socioeconomic factors like income, wealth, and education are beyond traditional medical care, but the growing evidence highlighting the critical role of socioeconomic variables in health cannot be ignored and should be explored accordingly [21]. Most studies on this topic have been conducted in high-income countries and have not widely explored parent-reported reasons for loss to follow-up. This study aims to examine factors contributing to loss to follow-up with special focus on social determinants while capturing the experiences of parents and caregivers.

2. Methodology

2.1. Study Design

This was a cross-sectional study.

2.2. Study Site

The study took place at the neonatology of Laquintinie Hospital in Douala (Cameroon). Laquintinie Hospital is a second-category hospital located in the centre of the city of Douala and is divided into several departments including the paediatric department. The paediatric department is divided into 5 units: the paediatric emergency unit, the general paediatric wards, the sickle cell unit, the outpatient consultation unit, and the neonatology unit. The neonatology unit is subdivided into three sub-units: prematurity subunit, Ashanti subunit (receives full term babies born within Laquintinie), and External neonatal unit (receives full term babies born out of Laquintinie). It receives roughly 200 neonates yearly.

2.3. Study Population

This study involved all neonates hospitalised at the neonatology unit of Laquintinie hospital. We included only parents/caregivers of neonates hospitalised at the neonatology unit of Laquintinie hospital during the study period who missed at least one follow-up visit and had never returned for follow-up. We excluded parents/caregivers who refused to participate in the study and/or whose neonatal records had missing essential data like date of admission, gestational age at birth, duration of hospitalisation, and clinical diagnosis, except otherwise provided by the parents/caregivers. We also excluded parents/caregivers whose

neonates were discharged against medical advice or referred to higher hospitals.

2.4. Study Duration and Period

This study was carried out over a 3-month period from Nov 2023-Jan 2024. The study period of interest spanned from 1st of January 2021 to 31st December 2022.

2.5. Recruitment Strategies

Parents were recruited in a convenient and consecutive manner. Data collection was done using a structured interview guide administered through a phone interview. After spanning through the registers over our study period, parents were called according to the period of hospitalisation of their neonates. This means that parents/caregivers whose neonates were hospitalised in January 2021 were called first while those whose neonates were hospitalised in December 2022 were called last. After detailed explanation of the purpose of the study, parents/caregivers were given the opportunity to ask questions and enrol immediately or postpone their enrolment at a more convenient time for them. Only parents/caregivers who granted their verbal consent were included in the study.

2.6. Data Tools

We used non-standardised structured interview guide conceived by the research team. The content of the interview guide was informed via a focus group discussion with 5 parents of neonates lost to follow-up to explore content validity and was modified accordingly after a pretest as displayed in the Appendix. Interview guides were used because of the anticipated difficulties to meet parents physically or send forms to their address.

2.7. Data Collection Procedure

Data collection also involved the use of hospitalisation registers and files to retrieve relevant information using a pre-established data collection form. Data on sociodemographic characteristics of the neonate, date of admission, gestational age at birth, duration of hospitalisation, and clinical diagnosis were collected from the registers, meanwhile, sociodemographic data of the caregiver/parent and data on reasons for loss-to follow-up were collected through the phone interviews.

2.8. Sample Size Calculation and Justification

Based on a study from Cambodia, a similar resource limited setting like Cameroon, the proportion of neonates lost to follow-up after discharge from the neonatal unit was 30% [22]. Thus, an overall minimum sample size of **323** patients was necessary for the study to have 80% power, significance of 5%, and 95% confidence interval. Based on yearly consultation frequency, we therefore designed this study to cover, at most, a 2-year period to reduce the risk of recall bias.

2.9. Data Analysis

Data was analysed using SPSS 20.0 software. Continuous variables were presented as the mean ± Standard Deviation (SD). Categorical variables were presented as numbers (percentage). Differences between continuous variables were analysed using the Student t-test. Associations between categorical variables were analysed using the Chi-square (X^2) test. Significance threshold was set at $p < 0.05$.

2.10. Ethical Considerations

Verbal consent was obtained from all participants prior to enrolment. The research data will remain confidential throughout the study such that no identifying information is made available to or accessed by anyone but the study investigators. All collected data were anonymised prior to analysis. Since no intervention was administered, the proposed study was unlikely to cause physical harm to the study participants. Administrative clearance was obtained from the Directorate of the LHD, and an ethical clearance was obtained from the Regional Human Health Research Ethics Committee for the littoral N: 2024/010/CE/CRERSH-LITTORAL.

2.11. Operational Definitions

Loss to follow-up: Absence to one or more programmed visit(s) with the physician after normal discharge from the neonatal unit and had never returned for follow-up.

Normal discharge: Discharge of a neonate from the neonatology unit requested by the physician because of better progress, and ability to follow-up treatment at home and report for normal routine visits. This does not include referrals to higher hospitals or discharge against medical advice.

3. Results

3.1. Patient Recruitment

A total of 1522 neonates were hospitalised during the study period. Of these, 504 patients were lost-to-follow up, giving us a percentage of 33.1%. From this total of neonates lost-to-follow up, 9.7% (n = 49) could not be contacted or had uncompleted files, and 455 neonates were finally included in our study.

3.2. Characteristics of the Mothers

The median age of the patients was 28 years (Q1 - Q3; 23 - 33) with a minimum of 15 years and a maximum of 45 years. The mothers had a median of 2 pregnancies (Q1 - Q3; 1 - 11) and attended a median of 4 antenatal clinic sessions (Q1 - Q3; 0 - 11). Most mothers were housewives (n = 135, 29.67%), had secondary level education (n = 235, 51.65%) and lived in Douala III (n = 205, 45.05%). Most mothers were living in cohabitation (n = 159, 34.95%), and beared singleton pregnancies (n = 346, 76.04%), Detailed sociodemographic and prenatal characteristics have been detailed in Table 1.

Table 1. Sociodemographic and prenatal characteristics of mothers of neonates lost to follow-up at Laquintinie from 1st January 2021 to 31st December 2022.

Characteristics of the mothers	**Median (Q1 - Q3)**
Mother's age in years	28 (23 - 33)
Number of ANC sessions attended	4 (0 - 11)
Number of pregnancies	2 (1 - 11)
Characteristics of mothers	**n (%)**
Profession	
Housewives	135 (29.67)
Self-employed	105 (23.08)
Employed	72 (15.82)
University students	53 (11.65)
Primary and secondary school students	38 (8.35)
Unemployed	47 (10.33)
Educational level	
No formal educational level	4 (0.88)
Primary level	63 (13.85)
Secondary level	235 (51.65)
Tertiary educational level	139 (30.55)
Residence	
Douala I	44 (9.67)
Douala II	36 (7.91)
Douala III	205 (45.05)
Douala IV	43 (9.45)
Douala V	102 (22.42)
Out of Douala	22 (4.84)
Marital status	
Cohabitation	159 (34.95)
Divorced	123 (27.03)
Married	115 (25.27)
Single	49 (10.77)
Widow	3 (0.66)
Types of pregnancies	
Singleton pregnancies	346 (76.04)
Twin pregnancies	99 (21.76)
Triplets	8 (1.76).

Q1 = 1st quartile, Q3 = 3rd quartile. ANC = Antenatal Care.

3.3. Characteristics of Neonates at the Time of Hospitalisation

Most neonates were born through vaginal delivery (n = 313, 69.45%). The neonates were admitted at a median gestational age of 33 weeks (Q1 - Q3; 32 - 35) with a minimum of 26 weeks and 41 weeks. Most patients were born preterm patients (n = 424, 93.19%) and only few neonates were born full term (n = 11, 2.42%). The median duration of hospitalisation was 12 days (Q1 - Q3; 8 - 18) with a minimum of 1 day and a maximum of 85 days.

3.4. Characteristics of Neonates at the Time of Interview

The median chronological age in weeks at the time of interview was 18 weeks (Q1 - Q3; 7 - 34) with a minimum of 1 week and a maximum of 72 weeks. The median corrected gestational age in weeks was 12 weeks and ranged from a minimum of -9 weeks and a maximum of 67 weeks.

3.5. Progress Post-Discharge

Most mothers considered that their neonate was growing normally (n = 366, 80.4%) while few reported growth retardation (n = 10, 2.2%) and a total of 23 neonates had died at the time of interview giving a mortality rate of 5.1% as shown in Figure 1. The three most commonly reported reason for loss-to-follow-up was lack of money (n = 310, 68.13%), assumption that follow-up had ended (n = 37, 8.13%), newborn that died (n = 23, 5.1%) as shown in Figure 2. Five patients reported that they were not satisfied with level of care.

4. Discussion

Our study aimed to determine the parent-reported reasons for loss-to-follow up in patients hospitalised at the neonatology unit of Laquintinie Hospital.

The proportion of loss to follow-up was 33.1% (n = 504/1522). Patra *et al.* in

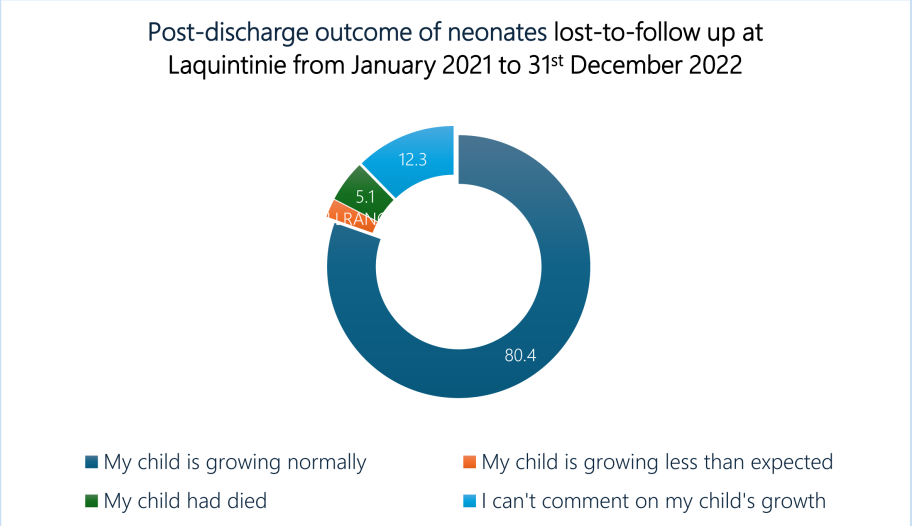

Figure 1. Post discharge outcome of neonates lost-to-follow up at Laquintinie from 1st January 2021 to 31st December 2022.

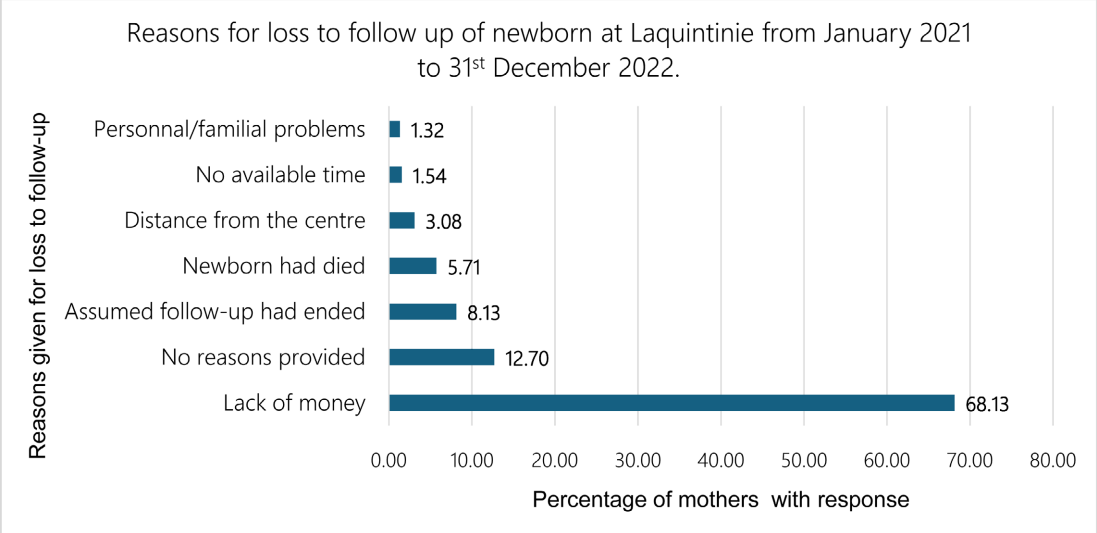

Figure 2. Post discharge outcome of neonates loss-to-follow up at Laquintinie from 1st January 2021 to 31st December 2022.

USA found that only 52% - 62% of very low birth weight infants attended their first follow-up visit, and this number decreased to 27% - 30% by 2 years of age [3]. Swearingen *et al.* in the USA had similar findings (62%) [1]. On the contrary, Ballantyne *et al.* in Canada reported a consistent non-attendance rate of 16% - 26% between clinic appointments [23]. These discrepancies may be related to the duration of follow-up in our setting and also on the fact that we considered proportions of all neonatal hospitalisations, not only preterm patients hospitalised in the Neonatal Intensive Care Unit (NICU) like exampled in Swearingen at al.'s report.

Neonatal follow-up clinics vary in their structures and services, but in Cameroon and at Laquintinie in particular, they commonly offer neurodevelopmental assessments, specialist consultancy (neuro-paediatrician, paediatric psychologist), access to social services, assistance in identifying medical issues, and support for managing infants with complex conditions as reported even in western countries [24]. Certain factors such as black race, distance from the hospital, maternal smoking or drug use, and socioeconomic factors have been recognised to contribute to poor attendance [1] [6] [7] [25] [26]. These results are in accordance with our findings as we found that a high proportion of parents reported financial constraints as the major cause of loss-to follow-up. The high rate of loss to follow-up due to financial constraints highlights potential socioeconomic barriers to healthcare access. Social determinants of health, such as the role of income, education, and housing in accessing follow-up care and programs to address financial barriers and improve follow-up rates, potentially through social support systems or financial assistance, could be explored. With the advent of the Universal Health Coverage proposed by the ministry of public health in Cameroon [27], this is expected to considerably reduce the proportion of loss to follow-up. Although most parents reported perceived normal growth post-discharge, it is primordial to conduct further studies to detailly analyse

long-term growth and developmental outcomes in these neonates.

It is quite alarming that a significant proportion of parents (8.13%) had assumed follow-up had ended. This raises the question about communication post-discharge as well as appointment management systems in resource limited settings where there is significant staff shortage, and records are still exclusively paper based. According to some authors, the utilization of online management systems has been shown to lower the occurrence of missed appointments, reduce staff workload, decrease waiting times, and enhance overall satisfaction, among other benefits. However, significant factors such as cost, adaptability, safety, and data integrity act as deterrents for providers when considering a transition to web-based scheduling [28].

Distance was also reported as a top reason for loss-to-follow-up (3.08%). Laquintinie is located in Douala I but only 9.87% of patients lived there. Most patients (Douala III and IV, 67.47%) had to travel from a very far distance to get to the centre for follow-up. These zones are devoid of secondary level facility equipped for neonatal care. Only Douala I (through Laquintinie) and Douala V (through Douala General Hospital) offer Level II special care nursery which encompasses providing mechanical ventilation for a brief duration or continuous positive airway pressure and similarly post-discharge expert level follow-up care [29]. This emphasizes the need for dissemination of high-level neonatal services in each major zones of Douala.

Because this study was monocentric, included only a few number of neonates, utilised a retrospective design to collect neonatal data which increases recall and recording bias, and used a convenience sampling method and phone interviews using a non-standardised collection tool, and the absence of inferential analysis, our results present a significant risk of bias and therefore cannot be generalisable to the overall population. Addressing these limitations through a multicentric prospective analytic cohort design in future studies can strengthen the generalizability of our findings. Additionally, qualitative research exploring the experiences of parents navigating financial barriers to healthcare would offer valuable insights.

Nonetheless, our study gives a voice to the parental narrative in exploring reasons for loss-to-follow-up. This insight provides preliminary findings that can serve for the drafting of specific health insurance models or follow-up care coordination strategies that address the identified barriers.

5. Conclusion

This study highlights the important impact of financial constraints and absence of a robust follow-up system on poor uptake of neonatal follow-up post-discharge in resource limited settings like Cameroon. Our results serve as advocacy for national health insurance especially in neonates. By addressing the proposed areas for further investigation, we can work towards improving follow-up care coordination strategies and long-term outcomes for these vulnerable populations.

Ethics Approval and Consent to Participate

Ethical clearance was obtained from the Regional Human Health Research Ethics Committee for the littoral N: 2024/010/CE/CRERSH-LITTORAL.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author, CEE.

Authors' Contributions

CEE and EMM conceived and wrote the protocol for this study. DMB did data collection. KDKMC supervised the study. EMM did data analysis for this study and wrote the draft manuscript. CEE, EMM, PDY, DMB and KDKMC revised the manuscript for scientific input. All authors agreed to submit the current manuscript as the final version.

Acknowledgements

We thank the administration of the administration of Laquintinie Hospital Douala, the personnel at the paediatric department and the parents for easing data collection procedures.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

References

[1] Swearingen, C., Simpson, P., Cabacungan, E. and Cohen, S. (2020) Social Disparities Negatively Impact Neonatal Follow-Up Clinic Attendance of Premature Infants Discharged from the Neonatal Intensive Care Unit. *Journal of Perinatology*, **40**, 790-797. https://doi.org/10.1038/s41372-020-0659-4

[2] Harmon, S.L., Conaway, M., Sinkin, R.A. and Blackman, J.A. (2013) Factors Associated with Neonatal Intensive Care Follow-Up Appointment Compliance. *Clinical Pediatrics* (*Phila.*), **52**, 389-396. https://doi.org/10.1177/0009922813477237

[3] Patra, K., Greene, M., Perez, B. and Silvestri, J. (2014) Neonatal High-Risk Follow-Up Clinics: How to Improve Attendance in Very Low Birth Weight Infants. *e-Journal of Neonatology Research*, **4**, 3-13.

[4] Tang, B.G., Lee, H.C., Gray, E.E., Gould, J.B. and Hintz, S.R. (2018) Programmatic and Administrative Barriers to High-Risk Infant Follow-Up Care. *American Journal of Perinatology*, **35**, 940-945. https://doi.org/10.1055/s-0038-1629899

[5] Litt, J.S., Halfon, N., Msall, M.E., Russ, S.A. and Hintz, S.R. (2024) Ensuring Optimal Outcomes for Preterm Infants after NICU Discharge: A Life Course Health Development Approach to High-Risk Infant Follow-Up. *Children*, **11**, Article No. 146. https://doi.org/10.3390/children11020146

[6] Fraiman, Y.S., Edwards, E.M., Horbar, J.D., Mercier, C.E., Soll, R.F. and Litt, J.S. (2023) Racial Inequity in High-Risk Infant Follow-Up among Extremely Low Birth

Weight Infants. *Pediatrics*, **151**, e2022057865.
https://doi.org/10.1542/peds.2022-057865

[7] Ballantyne, M., Stevens, B., Guttmann, A., Willan, A.R. and Rosenbaum, P. (2014) Maternal and Infant Predictors of Attendance at Neonatal Follow-Up Programmes. *Child: Care, Health and Development*, **40**, 250-258.
https://doi.org/10.1111/cch.12015

[8] Lakshmanan, A., Kubicek, K., Williams, R., Robles, M., Vanderbilt, D.L., Mirzaian, C.B., *et al.* (2019) Viewpoints from Families for Improving Transition from NICU-to-Home for Infants with Medical Complexity at a Safety Net Hospital: A Qualitative Study. *BMC Pediatrics*, **19**, Article No. 223.
https://doi.org/10.1186/s12887-019-1604-6

[9] Ravarian, A., Vameghi, R., Heidarzadeh, M., Nariman, S., Sagheb, S., Nori, F., *et al.* (2018) Factors Influencing the Attendance of Preterm Infants to Neonatal Follow up and Early Intervention Services Following Discharge from Neonatal Intensive Care Unit during First Year of Life in Iran. *Iranian Journal of Child Neurology*, **12**, 67-76.

[10] Orton, J., McGinley, J.L., Fox, L.M. and Spittle, A.J. (2015) Challenges of Neurodevelopmental Follow-Up for Extremely Preterm Infants at Two Years. *Early Human Development*, **91**, 689-694. https://doi.org/10.1016/j.earlhumdev.2015.09.012

[11] Mas, C., Gérardin, P., Chirpaz, E., Carbonnier, M., Mussard, C., Samperiz, S., *et al.* (2017) Follow-Up at Two Years of Age and Early Predictors of Non-Compliance in a Cohort of Very Preterm Infants. *Early Human Development*, **108**, 1-7.
https://doi.org/10.1016/j.earlhumdev.2017.03.001

[12] Kim, N.H., Youn, Y.A., Cho, S.J., Hwang, J.H., Kim, E.K., Kim, E.A.R., *et al.* (2018) The Predictors for the Non-Compliance to Follow-Up among Very Low Birth Weight Infants in the Korean Neonatal Network. *PLOS ONE*, **13**, e0204421.
https://doi.org/10.1371/journal.pone.0204421

[13] Catlett, A.T., Thompson, R.J., Johndrow, D.A. and Boshkoff, M.R. (1993) Risk Status for Dropping out of Developmental Follow-Up for Very Low Birth Weight Infants. *Public Health Reports*, **108**, 589-594.

[14] Piedvache, A., Van Buuren, S., Barros, H., Ribeiro, A.I., Draper, E., Zeitlin, J., *et al.* (2021) Strategies for Assessing the Impact of Loss to Follow-Up on Estimates of Neurodevelopmental Impairment in a Very Preterm Cohort at 2 Years of Age. *BMC Medical Research Methodology*, **21**, Article No. 118.
https://doi.org/10.1186/s12874-021-01264-3

[15] Chawla, D. and Suresh, G.K. (2014) Quality Improvement in Neonatal Care—A New Paradigm for Developing Countries. *Indian Journal of Pediatrics*, **81**, 1367-1372.
https://doi.org/10.1007/s12098-014-1406-7

[16] Ekwochi, U., Ndu, I.K., Nwokoye, I.C., Ezenwosu, O.U., Amadi, O.F. and Osuorah, D.I.C. (2014) Pattern of Morbidity and Mortality of Newborns Admitted into the Sick and Special Care Baby Unit of Enugu State University Teaching Hospital, Enugu State. *Nigerian Journal of Clinical Practice*, **17**, 346-351.
https://doi.org/10.4103/1119-3077.130238

[17] Lawn, J.E., Blencowe, H., Darmstadt, G.L. and Bhutta, Z.A. (2013) Beyond Newborn Survival: The World You Are Born into Determines Your Risk of Disability-Free Survival. *Pediatric Research*, **74**, 1-3. https://doi.org/10.1038/pr.2013.202

[18] Fleming, P.J. and Blair, P.S. (2003) Sudden Unexpected Deaths after Discharge from the Neonatal Intensive Care Unit. *Seminars in Neonatology*, **8**, 159-167.
https://doi.org/10.1016/S1084-2756(02)00222-1

[19] Carlo, W.A., Goudar, S.S., Pasha, O., Chomba, E., McClure, E.M., Biasini, F.J., *et al.* (2012) Neurodevelopmental Outcomes in Infants Requiring Resuscitation in Developing Countries. *The Journal of Pediatrics*, **160**, 781-785.e1. https://doi.org/10.1016/j.jpeds.2011.10.007

[20] Spittle, A., Orton, J., Anderson, P.J., Boyd, R. and Doyle, L.W. (2015) Early Developmental Intervention Programmes Provided Post Hospital Discharge to Prevent Motor and Cognitive Impairment in Preterm Infants. *Cochrane Database of Systematic Reviews*, **2015**, CD005495. https://doi.org/10.1002/14651858.CD005495.pub4

[21] Braveman, P. and Gottlieb, L. (2014) The Social Determinants of Health: It's Time to Consider the Causes of the Causes. *Public Health Research*, **129**, 19-31. https://doi.org/10.1177/00333549141291S206

[22] Honda, M., Som, R., Seang, S., Tung, R. and Iwamoto, A. (2019) One Year Outcome of High-Risk Newborn Infants Discharged from the Neonatal Care Unit of the National Maternal and Child Health Center in Cambodia. *Heliyon*, **5**, e01446. https://doi.org/10.1016/j.heliyon.2019.e01446

[23] Ballantyne, M., Stevens, B., Guttmann, A., Willan, A.R. and Rosenbaum, P. (2012) Transition to Neonatal Follow-Up Programs: Is Attendance a Problem? *The Journal of Perinatal & Neonatal Nursing*, **26**, 90-98. https://doi.org/10.1097/JPN.0b013e31823f900b

[24] Christner, L.P., Irani, S., McGowan, C., Dabaja, E., Dejong, C. and Attar, M.A. (2023) Previous Missed Visits and Independent Risk of Loss to Follow-Up in the High-Risk Neonatal Follow-Up Clinic. *Early Human Development*, **183**, Article ID: 105813. https://doi.org/10.1016/j.earlhumdev.2023.105813

[25] Fuller, M.G., Lu, T., Gray, E.E., Jocson, M.A.L., Barger, M.K., Bennett, M., *et al.* (2023) Rural Residence and Factors Associated with Attendance at the Second High-Risk Infant Follow-Up Clinic Visit for Very Low Birth Weight Infants in California. *American Journal of Perinatology*, **40**, 546-556. https://doi.org/10.1055/s-0041-1729889

[26] Fraiman, Y.S., Stewart, J.E. and Litt, J.S. (2022) Race, Language, and Neighborhood Predict High-Risk Preterm Infant Follow up Program Participation. *Journal of Perinatology*, **42**, 217-222. https://doi.org/10.1038/s41372-021-01188-2

[27] Accueil|CSU (Phase 1) [Internet]. https://csu.minsante.cm/

[28] Zhao, P., Yoo, I., Lavoie, J., Lavoie, B.J. and Simoes, E. (2017) Web-Based Medical Appointment Systems: A Systematic Review. *Journal of Medical Internet Research*, **19**, e134. https://doi.org/10.2196/jmir.6747

[29] Committee on Fetus and Newborn, Barfield, W.D., Papile, L.A., Baley, J.E., Benitz, W., Cummings, J., *et al.* (2012) Levels of Neonatal Care. *Pediatrics*, **130**, 587-597. https://doi.org/10.1542/peds.2012-1999

Appendix—Structured Interview Guide for Phone Interview Study

Topic: Parental-Reported Reasons for Loss-to-Follow Up in Patients Hospitalized at Neonatal Unit at Laquintinie Hospital

Introduction

Hello, thank you so much for taking the time to speak with me today. My name is [Your Name] and I'm calling from a research study at Laquintinie Hospital. The purpose of this study is to understand parents' experiences with follow-up care after their baby's stay in the neonatal unit. Your participation is completely voluntary, and all your responses will be kept confidential.

If you agree to participate and answer my questions, please say 'yes.' You are free to withdraw from the interview at any time.

Sociodemographic Information *(Collected from the file and confirmed from the parents)*

- Age;
- Gender;
- Marital status;
- Level of education;
- Occupation.

Neonatal Information *(Collected from the file and confirmed from the parents)*

- Briefly explain that you will ask some questions about their baby's stay in the neonatal unit;
- Gestational age at birth;
- Birth weight;
- Reason for neonatal admission (if comfortable sharing);
- Length of stay in the neonatal admission.

Follow-Up Care

- Were you given any follow-up appointments for your baby after discharge from the neonatal unit?
  - If yes:
    - How many follow-up appointments were you scheduled for?
    - Were you able to attend all of the scheduled appointments?
    - If no, why not? (skip to next question if yes)
  - If no:
    - Were you aware that follow-up appointments were recommended?

Reasons for Loss to Follow-Up (if applicable)

- Can you tell me why you were not able to attend all/any of the follow-up appointments? (Probe for specific reasons)
- Examples: Transportation difficulties, childcare issues, financial constraints, lack of understanding about the importance of follow-up, fear of bad news, cultural beliefs.

Closing

- Thank you again for taking the time to speak with me today. I really appreciate you sharing your experiences with follow-up care for your baby. Just to summarize, we talked about your baby's stay in the neonatal unit, the challenges you faced getting to the follow-up appointment, and how the hospital could improve fol-

low-up care for parents.

- Are there any questions you have for me about the study?

Notes

- This is a structured guide, but feel free to ask follow-up questions for clarification or to gain a deeper understanding of the parent's experiences.
- Maintain a sensitive and empathetic approach throughout the interview.
- Keep the interview concise, ideally lasting no more than 20-25 minutes.