ISSN 2526-8910
Cad. Bras. Ter. Ocup., São Carlos, v. 26, n. 1, p. 73-83, 2018
http://dx.doi.org/10.4322/2526-8910.ctoAO1027

Original article

Drop out in a clinic of preterm development follow-up: rates and causes

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Abstract: Objective: To make a survey of the dropping out rate and investigate its possible causes in preterm infants follow-up program. Method: Descriptive study, using the quantitative and qualitative methodology, developed in a follow-up preterm born children ambulatory. A survey of evasions occurred from January 2009 to December 2015 was done. Parents of children who dropped out were interviewed about the reason for evasion. To compare characteristics of children groups of drop out and follow-up, t-test (continuous variables) and chi-square test (categorical variables) were used, and content analysis was used for the data obtained in the interviews. Results: The overall rate of evasion over the seven years was 43.7%, reaching 60.5% when considering only children who entered in 2009. There were significant differences between drop out and follow-up groups in relation to age and education of the mothers. The interviews enable to identify reasons for evasion related to socioeconomic factors and health service organization. Conclusion: Better service organization, establishing routines and shared goals for the whole team, can contribute to maintaining the adhesion to the follow-up program. Multidisciplinary teams of follow-up programs, such as ACRIAR should recognize the social and family challenges faced by population served, being important to maintain a constant awareness work to raise awareness of the families about the necessity of the follow-up program.

Keywords: *Premature, Continuity of Patient Care, Lost to Follow-up.*

Evasão em ambulatório de seguimento do desenvolvimento de pré-termos: taxas e causas

Resumo: Objetivo: Realizar levantamento da taxa de evasão e investigar suas possíveis causas em programa de acompanhamento do desenvolvimento de recém-nascidos pré-termo. Método: Estudo descritivo, com uso de metodologia quanti-qualitativa, desenvolvido em ambulatório multidisciplinar de acompanhamento de crianças nascidas pré-termo. Foi feito levantamento das evasões ocorridas de janeiro de 2009 a dezembro de 2015. Pais de crianças que se evadiram foram entrevistados sobre o motivo da evasão. Para comparar características dos grupos de crianças de evasão e em seguimento foram usados teste-t (variáveis contínuas) e qui-quadrado (variáveis categóricas), e análise de conteúdo foi usada para os dados obtidos nas entrevistas. Resultados: A taxa global de evasão ao longo dos sete anos foi de 43,7%, atingindo 60,5% quando se considera apenas as crianças que entraram em 2009. Houve diferenças significativas entre os grupos de evasão e de seguimento em relação à idade e grau de instrução das mães. As entrevistas permitiram identificar motivos para evasão relacionados a aspectos socioeconômicos e à organização do serviço de saúde. Conclusão: Melhor organização do serviço, estabelecimento de rotinas e objetivos compartilhados por toda equipe podem contribuir para manter a adesão ao seguimento. Equipes multidisciplinares de programas de seguimento, como do ACRIAR, devem reconhecer os desafios sociais e familiares enfrentados pela população atendida, sendo importante manter trabalho constante de sensibilização das famílias acerca da necessidade do acompanhamento.

Palavras-chave: *Prematuro, Continuidade da Assistência ao Paciente, Perda de Seguimento.*

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Received on Nov. 20, 2016; 1st Revision on Aug. 12, 2017; Accepted on Sept. 26, 2017.

1 Introduction

Preterm children have biological vulnerability history and a higher risk of developing problems. A good part of these kids "apparently normal" can present deficits in motor areas, development in behavior and academic performance in long-term, when compared to children born at term (MOREIRA et al., 2014). The development of preterm infants is differentiated, since they are more susceptible to neurological and sensory deficits, with impact on the motor, cognitive and social development (MOREIRA et al., 2014; VIEIRA; LINHARES, 2011; RODRIGUES; BOLSONI-SILVA, 2011; MCGOWAN et al., 2011).

It is observed that up to 52% of children born prematurely and follow-up services have some development abnormality, during the follow-up diagnosed between 3 months and 8 years old (FERRAZ et al., 2010). Through specialized follow-up, it is possible to detect early changes in the development of babies at risk, enabling the prevention, referral to intervention and identification of emotional problems in children or in the family, besides to clarify the parents about the possible difficulties facing the care of children (FERRAZ et al., 2010).

Early detection of delays is important because interventions that occur during early childhood, besides bringing immediate and short-term benefits for the children's skills, can also create conditions to sustain these effects throughout the time (GURALNICK, 2012). Thus, premature follow-up programs are highly recommended and its continued service beyond the first years of life is of the utmost importance, since demands for performance increase with time and certain amendments to the development, as the learning disabilities, attention deficit disorder and motor coordination, just generally diagnosed with the entrance at school (DE KLEINE et al., 2003; LINHARES et al., 2004; FRAGA et al., 2008; VIEIRA; MELLO, 2009; FERRAZ et al., 2010).

Although necessary, follow-up programs often have to deal with abandonment and low-frequency of consultations by the assisted patients assisted (MAGALHÃES et al., 2002; FRÔNIO et al., 2009; TUDURI et al., 2011; VÁZQUEZ et al., 2011). When reviewing the literature on follow-up programs, it appears that the evasion is not a recent problem, being discussed for more than 20 years by Catlett et al. (1993). Data from published studies in different countries, including Brazil, reveal evasion rates ranging from 8% to 31% % (CATLETT et al., 1993; CALDERARI et al., 2001; MAGALHÃES et al., 2002; FRÔNIO et al., 2009; TUDURI et al., 2011; VÁZQUEZ et al., 2011).

The reasons that lead families to abandon the follow-up range from issues related to distance, family factors, such as lack of time or someone to take the child to the follow-up and lack of money for transportation, operational issues program, such as long waiting time, flaws in the consultation appointments and little information about the need of service (CATLETT et al., 1993; CALDERARI et al., 2001; MAGALHÃES et al., 2002; FRÔNIO et al., 2009; TUDURI et al., 2011; VÁZQUEZ et al., 2011). On the other hand, some families who abandon the multidisciplinary follow-up programs are follow-up services in other services, such as Basic Health Unit or private offices of Pediatrics, whose childcare service is considered enough for parents (FRÔNIO et al., 2009). It is noticed that there is no knowledge about the importance and necessity of the development follow-up, which seems to contribute to the evasion (MAGALHÃES et al., 2002; FRÔNIO et al., 2009).

Knowing the causes of evasion in preterm follow-up programs, it can contribute to the creation of more efficient strategies to encourage the adherence to this service, this study aimed to investigate the evasion rate on a development follow-up of newborn and its possible causes. The work was developed in an outpatient preterm follow-up, whose evasion rate in 1996 was 25.6%, and in 2000 was 20.3% (MAGALHÃES et al., 2002). As since that time there have been changes both in the follow-up protocol as well as on assistance to the population by the health system, it was considered appropriate to review the situation of evasions in the current scenario of public health care.

2 Methods

This is a descriptive study, using the quantitative and qualitative methodology to obtain numerical data about the circumvention and, at the same time, qualitative information to meet the reasons assigned by the parents for the evasion.

2.1 Procedures

This study was performed in the Ambulatory of the Child at Risk (ACRIAR), associated with the Hospital das Clínicas of the Federal University of Minas Gerais (HC/UFMG), created in 1987, which has structured follow-up routines from birth to seven years old, babies born in the maternity ward of HC/UFMG with gestational age ≤ 34 weeks and/or weight ≤ 1500 g. At the discharge of the maternity hospital, there is a schedule for the first pediatric and

nursing consultation in outpatient, when subsequent consultations and periodic evaluations rescheduled of Pediatric Neurology, speech therapy, occupational therapy and physiotherapy in ages-key until the seven years of age are made. In the service of physiotherapy and occupational therapy professionals and interns of both professions work together, conducting evaluations and guiding of the neuropsychomotor development and guiding the families.

The source of information was the ACRIAR database, in which, with the authorization of the families, all children referred to the physiotherapy and occupational therapy service are registered. Information on personal data, history, perinatal complications and family characteristics is collected, besides the results of evaluations of development, held to 2, 4, 8, 12, 18, 24 months, and annually until 7 years old. This database has started to be fed in 1996, and in the spring of 2016, there were 1559 registrations of children who have undergone ACRIAR development assessment. Initially, the records for all the families who had abandoned the service from 2009 to 2013 were located and tried to telephone contact. The families contacted were invited to return to ACRIAR and interviewed about the evasion reasons and the possible resumption of follow-up. As few families with evasion rate until 2013 were located, evasions surveys were done by the end of 2015, to encompass a whole seven-year period of follow-up.

The data of all preterm babies born in the HC/UFMG and registered in the database of physical and occupational therapy service of the ACRIAR from January 2009 to December 2015 were included in the study. Also, as already described, parents of preterm children born in HC/UFMG and registered in ACRIAR who have left the follow-up of development in the period 2009 to 2013 participated in the study. To consider service evasion, the child should submit three consecutive missing consultations of physiotherapy and occupational therapy, even after attempting to telephone contact to reschedule.

To locate families who have evaded from the service from 2009 to 2013, a search the ACRIAR database of the records of evasion, located the original records, on paper, to obtain the address and phone number was made. To record the evasion data in the spreadsheet program, Excell (14.5.2 version) was used containing the patient's code, chart number, child's name, date of birth, neonatal conditions, mother's name, address, contact phone number and the date of when they appeared for the last time to attend physiotherapy and occupational therapy. All phones found on the records were registered and made an attempt to telephone contact with all the families who have left the program was made. For families found, the objectives of the study were explained and an invitation to participate in an interview on ACRIAR was done, with the goal of identifying the reasons for the follow-up abandonment. A guide was elaborated to open interview about the reasons for evasion, and the number of interviews is defined by the availability of the parents for coming to ACRIAR, ending the collection when it has not been possible to find more families or when those located did not attend the interview.

All the interviews were recorded on audio equipment (Sony Digital Voice Recorder), with permission of the participants, and transcribed in full by the first author. To ensure confidentiality, the words of the participants were coded E1, E2, E3 and so on, according to the order of conducting the interview.

Demographic data relating to evasion from 2009 to 2015 - code, number of medical records of the child, name, date of birth, gestational age, gender, weight, address, region of residence, year of entry into ACRIAR and date of evasion - were taken from the ACRIAR database, constituting new worksheet Excell (14.5.2 version). The data were conferred with original records of the children, with encoded evasions, discharge, detachment, which usually occur by the change of city, and children in follow-up. Discharge and detachment were recorded as being monitored because in these cases there was no service abandonment.

The subsequent project and amendment were approved by the Ethics and Research Committee of the Federal University of Minas Gerais - COEP/UFMG (Opinion Nº 1,160,701). All participants in the study were informed about the procedures and objectives of the study and signed the Informed Consent Form. The parents of all the children who attend ACRIAR are informed about the research activities carried out in the service and about the constitution of the database. The data are collected only from the children whose parents agree to participate in research, keeping the same quality of care for who does not participate in such activities.

2.2 Data analysis

The quantitative data were analyzed with the program Statistical Package for Social Sciences (SPSS) for Windows (version 19) with the calculation of averages and simple frequency. To compare the characteristics of the children who remain in the follow-up and those who left the program, Student´s t-test for continuous variables and Chi-square test

were used for categorical variables. In all comparisons, significance level $p \leq 0.05$ was considered.

The qualitative data were analyzed through the technique of content analysis proposed by Bardin (1977, p. 105), a technique that

> [...] is to discover the nuclei of the meaning of the communication and whose presence, the frequency of appearance, can mean something for the chosen analytical objective [...].

In the analysis of the data, it was sought to discuss the aspects related to evasion in articulation with the literature.

3 Results

3.1 Evasion survey

From January 2009 to December 2015, there were 446 new cases of preterm infants registered in the physiotherapy and occupational therapy service of ACRIAR, of which 195 (43.7%) evaded. In the follow-up group, consisting of 251 children, 127 (50.6%) were boys and 124 (49.4%) were girls. In the evasion group, 108 (55.4%) were girls and 87 (44.6%) were boys.

In Table 1 on the characterization of the follow-up and evasion groups, it can be observed significant differences between the groups in only two of the investigated variables. The mothers´ age was lower in the evasion group, and in the follow-up group, there was a higher frequency of mothers with complete high school and higher education. Regarding the region of residence (Table 1), most families live in Belo Horizonte (BH) or Grande BH, and there was no significant difference between the evasion and follow-up groups regarding housing in Belo Horizonte and in cities in the interior.

As can be seen in Table 2, there was variation in admissions for follow-up, with more referral to ACRIAR in 2009 and 2010. Considering the children who entered in 2009, during the seven years of follow-up (Figure 1), the highest percentage of evasions of the development follow-up, 12 (26.1%) occurred during the second year of life, and 80% of the evasions occurred by the end of the fourth year of life.

Table 1. Characterization of the total sample and groups in follow-up and avoidance in the period from 2009 to 2015 in ACRIAR.

Group characteristics	Total	In follow-up	Evasion	p[t]
Gestational age	31.02 (±2.305)	31.12 (±2.43)	30.9 (±2.13)	0.300
Amplitude	24-37	24-37	24-35	
Birth weight	1454.32 (±425.79)	1459.69 (±451.29)	1447.54 (±392.26)	0.766
Amplitude	515-2890	515-2515	640-2890	
Mother's age	28.42 (±7.69)	**29.09 (±7.34)**	**26.86 (±6.87)**	**0.002**
Amplitude	14-58	**15-49**	**14-42**	
Father age	31.41 (±8.22)	31.83 (±8.16)	30.81 (±8.29)	0.229
Amplitude	15-63	16-54	15-63	
Overall income - number of wages	2.55 (±1.62)	2.49 (±1.71)	2.63 (±1.48)	0.446
Amplitude	1 to 15	1 to 15	1 to 10	
Age in months	23.63 (±17.30)	19.92 (±19.67)	23.71 (±17.43)	0.668
Amplitude	1.2-73.76	6.13-48.90	1.2-73.76	
Educational level of mothers*				
Illiterate	11 (2.8%)	**3 (1.3%)**	**8 (4.9%)**	
Incomplete elementary school	80 (20.2%)	**46 (19.7%)**	**34 (20.9%)**	**0.001**[x]
Complete primary education	56 (14.1%)	**31 (13.2%)**	**25 (15.3%)**	
Incomplete high school	58 (14.6%)	**22 (9.4%)**	**36 (22.1%)**	
Complete high school	158 (39.8%)	**109 (46.6%)**	**49 (30.1%)**	
Higher	34 (8.6%)	**23 (9.8%)**	**11 (6.7%)**	
Region of residence				
Greater Belo Horizonte	260 (75.6%)	149 (74.1%)	111 (77.6%)	0.417[x]
Metropolitan Interior and Necklace	84(24.4%)	52 (25.9%)	32 (22.4%)	
Total	446 (100%)	251 (56.3%)	195 (43.7%)	

Note: t-Test; x Qui-square; * Illiterate category was combined with incomplete elementary school for analysis.

3.2 Reasons for parents´ evasion

In the preliminary survey conducted from 2009 to 2013, there were 181 evasions identified, of which it was not possible to locate 151 families since the contact telephones that appeared on the ACRIAR records were outdated or did not exist. Ten of the 30 families contacted were willing to return to ACRIAR for a face-to-face interview, of which six were on the scheduled date: one father and five mothers. Table 3 presents the characterization of interview participants and their babies.

In the analysis of the qualitative data, three thematic categories were identified: (Un) knowledge of the needs of the child, Logic of operation of the service and Organization demanded to go to the consultations. The categories, their respective subcategories, and reports of parents are presented in Table 4.

Table 2. Mapping of evasions in the follow-up of development in ACRIAR in the period from 2009 to 2015.

Year	Admissions	Follow-up	Discharge	Disconnected	Evasion	Mean of age in evasion(in months)	DP
2009	76	20 (26.3%)	8 (10.5%)	2 (2.6%)	46 (60.5%)	32.45	19.21
2010	76	26 (34.2%)	14 (18.4%)	1 (1.3%)	35 (46.1%)	30.46	18.34
2011	68	19 (27.9%)	5 (7.4%)		44 (64.7%)	23.96	17.07
2012	73	30 (41.1%)	6 (8.2%)	1 (1.4%)	36 (49.3%)	16.61	11.59
2013	48	27 (56.3%)	1 (2.1%)		20 (41.7%)	13.60	6.68
2014	59	44 (74.6%)	1 (1.7%)		14 (23.7%)	8.18	4.68
2015	46	46 (100%)					
Total	446	212 (47.5%)	35 (7.8%)	4 (0.9%)	195 (43.7%)	23.63	17.43

Table 3. Characterization of parents interviewed about the reasons for avoidance of ACRIAR and their babies.

	Age	Education level	Weight of the baby	Gestational age
E1	24 years old	Complete high school	1380 g	29 weeks
E2	25 years old	Incomplete high school	1015 g	31 weeks
E3	37 years old	Complete primary education	2020 g	34 weeks
E4	32 years old	Illiterate	1860 g	32 weeks
E5*	38 years old	Incomplete high school	2305 g	33 weeks
E6**	31 years old	Complete high school	G1: 1245 g	31 weeks
			G2: 1615 g	31 weeks

Note:* E5 corresponds to the interview with one parent, the others are mothers; **Mother of twins.

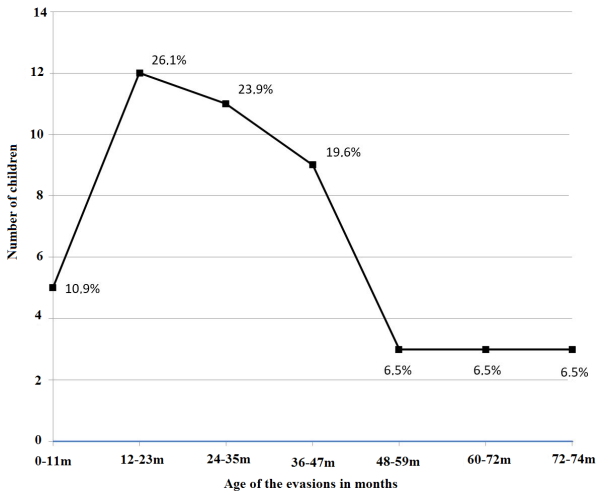

Figure 1. Evacuation frequency curve for developmental follow-up among children admitted to ACRIAR in 2009.

Table 4. Thematic categories and subcategories obtained through the analysis of the interviews with parents of children who evasion from ACRIAR.

Categories	Subcategories	Parents´ reports*
(Un) knowledge of the child's needs	Parents' lack of knowledge about the need for continuity of outpatient follow-up of the child	*"The question of not knowing that he needed to continue the treatment"* (E5) (Fragment A).
	Recognition of the need to follow-up the baby at risk	*"I see that I have this need, but the time is too short, it's too much of a rush. Sometimes, to solve something else, I find it difficult to find someone to look at, right?"* (E6) (Fragment B).
Service operation logic	Consultation scheduling overlap	*"Schedule, because it seems to give to everyone a single schedule and there is that fight on a first come, first served basis. Then it's the whole afternoon to spend in a room to weigh, to pass in another room. Sometimes it's a physio, TO and pediatrician, so we do not know if he's there or he's waiting on the bench"* (E1) (Fragment C).
	Organization of the service	*"Because we come here, I do not know if they were giving preference more to who is from the interior to be able to leave faster, because the issue of ambulance these things, and we always stayed, so I had to give up the consultation, we arrived here, it was not even noon right, I had to stay, there is a consultation down there, then you go up, there is the time to weight"* (E4) (Fragment D). *"The pediatrician came in, retired and TO was waiting for a response from the pediatrician, and it turned out that he did not even consult with the pediatrician or with TO because he did not have a call from someone"* (E2) (Fragment E).
	Waiting time	*"The only bad thing is that it takes too long"* (E1) (Fragment F). *"You lose pretty much all day here in the hospital, right?"* (E4) (Fragment G). *"There's time we get here, especially in the afternoon, right? We arrive here, it's scheduled for one hour and it's only taken care of at 3:00 a.m."* (E5) (Fragment H).
	Communication established between health professionals and the family	*"In fact, we were not coming because at the last consultation she came, I do not know who spoke to her, that she was released"* (E5) (Fragment I).
Organization requested to go to consultations	Expenses with going to the consultation	*"Most of the time, the next person also does not have the conditions, he comes here without lunch, without having a coffee and he is hungry all day. It did not happen to me, but I've seen people complaining that they have a headache with hunger until they get home"* (E5) (Fragment J).
	Difficulty of movement	*"I changed the interior, I had no way to bring them in the consultations"* (E1) (Fragment K). *"But I live in São Pedro da União (MG) and it's 5 hours away. It is difficult, he saw"* (E2) (Fragment L). *"How do I carry two children on my lap, a little baby and bag inside the bus, I can´t"* (E6) (Fragment M).

*To enable the identification of the reports used in the discussion, they were coded in alphabetical order: Fragments A, B, C ... M.

4 Discussion

The data show that evasion is high, with an overall rate of 43.7%, considering the total sample, and reaching 60.5%, when considering seven years of follow-up, as presented in Table 2. In Table 1, we can see that the mean gestational age of the evasion group is worrisome, 30.9 weeks, corresponding to the classification of the extreme preterm (CARBONERO; ALONSO, 2009), and

the average birth weight of 1,447.54 g is also low, indicating that the population is vulnerable and needs follow-up (MOREIRA et al., 2014).In both Table 1 and Table 1, it can be observed that there were no statistically significant differences between the follow-up and evasion groups regarding birth weight, gestational age, mean age of the groups, family income and age of the parents, that is, both of them are medium to high biological risk groups, due to prematurity, and also social risk, since they are families with an average income of 2.5 minimum wages (RUGOLO, 2005). Table 1 shows that there was a difference between groups only in the age of the mothers, which was lower in the preterm group, leading to the hypothesis that perhaps younger mothers need more support for continuity of follow-up.

There was also a difference in the mothers´ educational level (indicated in Table 1), which in the follow-up group, there was a higher frequency of mothers with complete secondary school and higher education. However, a similar level of education of the mothers in the preterm follow-up groups has been found, and they have abandoned programs of follow-up, with a better adherence (FRÔNIO et al., 2009). However, a similar level of education of mothers has been found in the preterm follow-up groups, and they have abandoned follow-up programs (CATLETT et al., 1993; FRÔNIO et al., 2009; TUDURI et al., 2011). The creation of strategies that can effectively reach this group of participants with low levels of education, making information more accessible and relevant to the assisted population is a challenge for pre-committee follow-up program teams (FRÔNIO et al., 2009).

Another important thing in the characteristics of the groups is the fact that, in both groups, most of them reside in Belo Horizonte and the metropolitan region (Table 1). Although in the interviews the distance factor was cited as a difficulty for the frequency of consultations, the number of families residing in the interior and with greater difficulty in accessing the service was similar in the follow-up and evasion groups. However, it is understood that long journeys, even in the metropolitan area, bring extra costs for this population besides to being tiresome, since the families not only need the transportation but also have to pay for food and other necessities in the time of transfer and waiting, according to cited by the interviewees.

The distance of the hospital as one of the reasons for the evasion is also reported in other studies (FRÔNIO et al., 2009; VÁZQUEZ et al., 2011). In the study by Catlett et al. (1993), the provision of transportation is recognized as a strategy that contributes to the maintenance of attendance at outpatient clinics, which already occurs in ACRIAR, since the families of the interior generally use the transportation offered by the cities of origin. The quality of this transportation could not be evaluated since almost all the families interviewed were from the capital city (except one). However, there were complaints of difficulties in the use of public transportation and the delay in attendance, with the release of families to return home in hours of heavy traffic, when buses are full, making transportation of children unviable.

A solution to this problem, cited in several studies as in Catlett et al. (1993), Calderari et al. (2001), Magalhães et al. (2002) and Frônio et al. (2009) would review the logistics of offering follow-up programs, still very focused on the hospital model, as in the case of ACRIAR and all the studies cited, and invest in services closer to the family home. Investing in the organization of the health network, it would facilitate access and close proximity between family and follow-up team, contributing to fewer and fewer at-risk children without follow-up.

In the studies by Frônio et al. (2009) and Tuduri et al. (2011), which also sought to understand, identify and characterize the group of preterm that evaded follow-up services, the factors related to evasion were very similar to this study, as well as the characteristics of the samples, showing that it is necessary to consolidate the follow-up service between the various health professionals and patients to raise awareness among families about their importance and the team about their complexities. Also, it is recommended that the search for an understanding of the factors leading to evasion be constant, to intervene more quickly and effectively to maintain the frequency in the follow-up program (FRÔNIO et al., 2009; TUDURI et al., 2011).

The overall evasion rate (Table 2) found in this study is above the values reported in the studies in the area, ranging from 8% to 31% (CATLETT et al., 1993; CALDERARI et al., 2001; MAGALHÃES et al., 2002; FRÔNIO et al., 2009; TUDURI et al., 2011; VÁZQUEZ et al., 2011). Although the characteristics of the groups investigated (Tables 1, 2 e 3) and the evasion reason (Table 4) were very close, most of the evasion rates found in Catlett et al. (1993), Calderari et al. (2001), Tuduri et al. (2011), Vázquez et al. (2011), refers to programs from six months to two years of follow-up, well below the seven years investigated. When considering only the first 24 months (Figure 1), evasion was 26.6%, which is similar to the studies reviewed.

In the period investigated, the year with the highest number of evasions was 2009 (Table 2), because in this case, evasion is counted throughout a follow-up period, that is, only 40% of the children remain in the program until 7 years old, with most abandoning follow-up up to 36 months, with a higher evasion rate between 12 and 24 months. Other studies also report that a relative part of children evades programs between 12 and 24 months (TUDURI et al., 2011). Evasion at this age may be associated with the fact that, since children have already acquired gait and speech, this suggests to the parents that the development is within the expected, and no further follow-up is necessary. This is a cause for concern, since more subtle developmental disorders, such as deficits in attention and motor coordination, are only diagnosed at school age, and parents need to be told about this possibility (MOREIRA et al., 2014).

In a previous study performed at ACRIAR by Magalhães et al. (2002), the rate of evasion was lower, ranging from 20.3% to 25.6%. It is seen that the number of evasions has practically doubled from 2002 to 2015, and it is necessary to investigate what happened during this period, which led to an increase in evasion. One hypothesis is that informational strategies, such as leaflets for parents and restructuring of the first consultation with time dedicated to guide and explain the program, implemented between 1996 and 2000 to increase adherence to the program in the study of Magalhães et al. (2002), were abandoned, as suggested by the mothers' speech, which report a certain discontinuity in the orientations to the families, generating doubts as to the necessity of the program and to continue the consultations. Another relevant fact is that, in recent years, the government has invested in networked health care, and families have more access to pediatric consultations in health centers in their neighborhoods. In a study conducted in Juiz de Fora/MG by Frônio et al. (2009), it was observed that some families did not have a follow-up of child care in Basic Health Units, disregarding the importance of follow-up with the specialized multidisciplinary team. It must be verified that this hypothesis also corresponds to reality in the case of ACRIAR.

The reasons why the interviewed families report having abandoned follow-up are also similar to those previously reported by Magalhães et al. (2002), which is another factor of concern, because once these motives are recurrent, strategies to reduce evasion have either been abandoned, as previously discussed, or the frequency of follow-up has not been guaranteed.

The lack, lack of clarity or misunderstandings of information, as well as few guidelines on the need for multidisciplinary follow-up, appear as other aspects that contributed to the evasion. In the interviews, the parents appeared to be unaware of the need for continuity of the outpatient follow-up of the child (Fragment A).

Despite this, the data suggest that there is recognition of the need to monitor the baby at risk. However, in contrast to the other daily activities and the fragility of the support network, it is not possible to continue the outpatient follow-up (Fragment B).

These same reasons were also reported in the study by Magalhães et al. (2002) on evasion in ACRIAR, as well as other authors such as Frônio et al. (2009) and Tuduri et al. (2011). As expressed by the parents interviewed, although there is recognition of the need for preterm follow-up, non-adherence to outpatient follow-up suggests that only recognizing the need for follow-up does not determine the frequency of families in the program, this need to be in fact better clarified

Participants also pointed out that the waiting time for the consultations demanded to remain for long periods in the hospital, which discourages the frequency in the outpatient follow-up (Fragments F, G, and H).

Both in the interviews conducted in this study and in data from the study by Frônio et al. (2009), it was reported that waiting time is one of the factors that contribute to alienating families.

Another question elucidated by the interviewees refers to the excessive number of appointments scheduled for the same time with different specialties, as well as the logistics for the service to the patients of the interior. Although all children are scheduled for the same time, there seems to be a priority for attending those coming from the interior, increasing the waiting time for those who live in the capital (Fragment C).

The absence of scheduling and first-order care was also reported as a reason for evasion in a previous ACRIAR study by Magalhães et al. (2002), and it is a common practice in public health services, as cited by Moimaz et al. (2010), which denotes the organization of the provision of services according to the convenience of the health team and not focused on the needs of families, which should be reviewed.

Another aspect related to evasion is the communication established between health

professionals and the family, which sometimes does not occur clearly, leading to the understanding that follow-up is complete (Fragment I).

The turnover of professionals was also pointed out by the families as another compromising aspect of the program frequency. The rotation is common in health services in Brazil, especially in school hospitals, as is the case of the outpatient clinic in question. Each semester new bonds are formed and broken, causing the family to go unreported. It is important that practitioners seek to establish lasting bonds and relationships of mutual trust with families to extend care by supporting the family through a new look at the follow-up of these infants and families, who are in a conflicting situation (BENGOZI et al., 2010).

The participants´ report also suggests that evasion may be related to the organization of the service, in order to ensure continuity of care, especially in situations where there was a change in the care team (Fragment E).

Added to this, the visit to the consultations entails expenses, such as those related to food. However, not all families have the financial means to pay for these expenses, which can hinder to go to the clinic (Fragment J).

The fact of residing in another city, as well as the difficulty of moving to the consultations, also appears as a commitment to attendance in the follow-up program (Fragments K, L, M).

The fragility of the family support network, which is evident in the speeches that report on the absence of people to support the children in the absence of the mother or even to take the child to follow-up, is also a reason for evasion. In this sense, it is up to the health professional to support families in order to build care possibilities that favor the child's growth and development (SASSÁ; MARCON, 2013). The specificities of preterm newborn care require a reorganization of family dynamics and, in these situations, the support network favors coping with the difficulties inherent in this process, as well as meeting the needs of the child (SASSÁ; MARCON, 2013).

Also, as discussed in some studies by Linhares et al. (2004), Frônio et al. (2009), Becker et al. (1972 apud CATLETT et al., 1993), practices favoring the link between family and health professionals, such as home visits before hospital discharge and continuity of care by the same professional, can increase the frequency of the children in outpatient follow-up.

In general, the interviewees' reports reveal that the reasons related to evasion of the follow-up program correspond to socioeconomic aspects, such as financial difficulty, fragility of the support network, and aspects related to the organization of the health service, such as communication between professionals and families, organization of the service to ensure continuity of appointments and schedules of appointments at the same time.

5 Conclusion

It is important that the multidisciplinary team of the follow-up program recognize, during the years of follow-up, the existence of social and family problems, using social assistance whenever necessary. It is also recommended that the preterm follow-up service maintain constant awareness-raising work on the need for follow-up in order for them to increasingly understand the importance of follow-up.

This study has limitations since a single follow-up program was investigated, for a limited period of time. However, it was possible to report follow-up data for seven years, from entry to discharge of the program to a group of children. The mobility of families and the difficulty of retaining the same telephone number have limited the possibility of locating families. Despite the small number of respondents, the reports, added to the quantitative data, provided relevant and complementary information.

The results of this study indicate some strategies that may contribute to maintaining adherence to follow-up, such as reviewing the organization of the service, in terms of scheduling consultations, optimizing the time spent by families in follow-up, and improving inter-professional communication, establishing routines and goals shared by all staff, to avoid inconsistencies in communication with families. Promoting parental involvement, especially by informing them of the risks and possible delays in the development of the preterm baby, they can have a significant impact on adherence. Families with a smaller social support network and babies of younger mothers should be identified to optimize the resources offered and adapt follow-up to minimize abandonment. The decentralization of the follow-up programs, expanding them to other regions of the state and to the regional ones of the city, would facilitate the access, would reduce the displacement, promoting the adherence to the follow-up. Constant follow-up allows the control of evasions, as well as providing data for comparison between different

programs. Future studies should investigate the factors associated with high ACRIAR evasion rate, whether this was an isolated fact and whether other programs also observed the same phenomenon.

Acknowledgements

To the assisted families and to the team of ACRIAR, without them, it would not have been possible to do this work. CNPQ and CAPES, for the financial support to the project.

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Author's Contributions

The authors of the article had equal participation in the conception and delineation of the study, in the production of the data, statistical analysis, preparation, writing and final critical review of the work. All authors approved the final version of the text.

Funding Source

CAPES, CNPq.