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Methods Used To Maximize Follow-up: Lessons Learned from the Therapeutic Hypothermia After Pediatric Cardiac Arrest Trials

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Abstract

Objective: To describe telephone interview completion rates among 12-month cardiac arrest (CA) survivors enrolled in the Therapeutic Hypothermia after Pediatric Cardiac Arrest In-Hospital (THAPCA-IH) and Out-of-Hospital (THAPCA-OH) trials, identify key characteristics of the completed follow-up interviews at both 3- and 12-months post-CA, and describe strategies implemented to promote follow-up.

Setting —Centralized telephone follow-up interviews.

Design—Retrospective report of data collected for THAPCA trials, and summary of strategies used to maximize follow-up completion.

Patients —12-month survivors (n=251) from 39 THAPCA PICU sites in the USA, Canada, and United Kingdom.

Interventions —Not Applicable Measurements and Main Results – The 3- and 12-month telephone interviews included completion of the Vineland Adaptive Behavior Scales, Second Edition (VABS-II). VABS-II data were available on 96% (242/251) of 3-month survivors and 95% (239/251) of 12-month survivors with no differences in demographics between those with and without completed VABS-II. At 12 months, a substantial minority of interviews were completed with caregivers other than parents (10%), after calls attempts were made on six or more days (18%), and during evenings/weekends (17%). Strategies included: emphasizing the relationship between study teams and participants, ongoing communication between study team members

across sites, promoting site engagement during the study's final year, and withholding payment for work associated with the primary outcome until work had been completed.

Conclusions —It is feasible to use telephone follow-up interviews to successfully collect detailed neurobehavioral outcome about children following pediatric CA. Future studies should consider availability of the telephone interviewer to conduct calls at times convenient for families, using a range of respondents, ongoing engagement with site teams and site payment related to primary outcome completion.

Keywords

pediatric critical care; follow-up rates; outcomes; cardiac arrest; randomized control trial

INTRODUCTION

Fewer than 300 randomized controlled trials (RCTs) have been published in critically ill children worldwide (1). Common barriers to research in this population include lack of funding, few established pediatric critical care networks and parents' concern about the risk of harm to their children (2). In addition, many patient populations of interest in the pediatric critical care community are low incident groups necessitating multi-center trials, which can be expensive and require additional resources for coordination. Moreover, in both single and multi-center trials, long-term outcome data collection is particularly challenging (2, 3). As a result, most studies have focused on short-term, global outcomes, described as "favorable" versus "poor" at time of hospital discharge as the primary outcome measure (4).

Two recent, parallel RCTs, the Therapeutic Hypothermia after Pediatric Cardiac Arrest (THAPCA) Trials, were conducted to study the effect of temperature control after out-of-hospital cardiac arrest (THAPCA-OH) and in-hospital cardiac arrest (THAPCA-IH) by comparing the efficacy of therapeutic hypothermia to therapeutic normothermia in comatose survivors of pediatric cardiac arrest (CA). While the primary outcome of the THAPCA trials was dichotomous (favorable vs. unfavorable outcome at one year), a novel component of the THAPCA trials was telephone-based collection of a detailed neurobehavioral assessment in 12-month survivors as part of the primary outcome. Favorable outcome was defined as survival to 12-months post-CA with a score broadly within the average range on a standardized semi-structured interview measure of caregiver-reported daily functioning, collected by a trained interviewer at a centralized telephone follow-up center.

Collecting detailed neurobehavioral outcomes 12-months post-CA remained challenging even with involvement of two national pediatric emergency and critical care networks, a Data Coordinating Center (DCC), a centralized telephone outcome center, and National Institute of Health funding. Barriers included the large number of enrolling sites, the duration of time between CA and follow-up, the lengthy interview required for each child's daily functioning, the participants' wide age range, and the varied outcomes from neurologically devastated to neurologically normal. To ensure adequate power and generalizability of findings, several strategies were employed to maximize retention for those children whose parents initially provided consent under stressful, time-sensitive circumstances (i.e., by 6 hours after their child's CA). Low follow-up rates may adversely

affect trial findings, over and above simply reducing statistical power due to fewer subjects with outcomes, by possibly making findings non-generalizable or biased (5).

In this paper, we describe the telephone interview completion rate in 12-month THAPCA trials survivors, identify the key characteristics of the completed telephone interviews at both 3- and 12-months post-CA, and describe strategies employed to promote follow-up. Delineating these details about THAPCA trials outcomes data collection may be helpful to researchers designing future pediatric critical care clinical trials with similar outcomes.

METHODS

Overview of the THAPCA Trials Outcomes Data Collection

Both THAPCA trials began in September 2009. THAPCA-OH enrolled ahead of schedule and met its recruitment goal in December 2012 (6). Recruitment in THAPCA-IH enrollment was slower than anticipated and the study closed due to futility in February 2015 (7).

Each enrolling study site (37 for IH; 36 for OH) had a site principal investigator (PI) and research coordinator (RC). In general, a site's financial support initially included the following: 1) effort for a RC and effort for the site PI; 2) specific stipend milestone payments for screening and subject enrollment; and 3) for hospital survivors, additional stipend milestone payments were allocated for completion of the 3- and 12-month VABS II, as well as onsite neurological exam and neuropsychological testing. Beginning March 1, 2013, effort support for the RC and site PI was eliminated and the stipend payments for enrollments and survivor milestones were increased.

Both trials had sites in the United States and one in Canada; United Kingdom sites enrolled in only THAPCA-IH. The Data Coordinating Center was at the University of Utah and the Outcomes Center was located at the Kennedy Krieger Institute (KKI) in Baltimore, Maryland. Trials were approved by Institutional Review Boards at all sites, and Data Coordinating and Outcomes Centers.

The primary outcome was survival at 12 months with good neurobehavioral outcome defined as scores not more than 2SD below the age-corrected standard score mean (i.e., scores ≥ 70) using the Vineland Adaptive Behavior Scales, Second Edition (VABS-II) (8). The VABS-II measures caregiver report of functional skills and provides age-corrected standard scores (mean=100, SD=15) in four domains (communication, daily living, socialization, motor skills) and an overall adaptive behavior composite. The VABS-II was collected at 3- and 12-months post-CA via telephone by a trained interviewer at KKI. The use of a trained VABS-II interviewer at a central follow-up center was employed to maximize the reliability of data collected. Interviewers had a minimum of a master's degree in psychology and were trained specifically on using the VABS-II by the supervising neuropsychologist (BS).

The KKI interviewer, who conducted the majority of the follow-up calls, had 50% effort dedicated to THAPCA. To ensure reliability, the first four interviews, followed by every 10th interview were audio-recorded and reviewed by the supervising neuropsychologist (BS). The

interview typically lasted 30 to 45 minutes depending upon the subject's functioning age and was completed during one call. Calls took less time for younger children or those with poor functional status, as in those settings there were fewer relevant VABS-II questions to administer.

The VABS-II respondent had to be an adult familiar with the child's everyday behavior, have frequent contact with the child over an extended time period, and speak either English or Spanish. A parent was usually the most appropriate respondent; however, for children living in a residential facility, the respondent could be a healthcare provider who knew the child well.

The DCC, KKI and enrolling THAPCA sites followed a detailed protocol to complete the follow-up evaluations on time and with consistency. To begin the process, the site RC contacted the participant's family two to four weeks prior to the evaluation to confirm the participant's vital status, identify an appropriate respondent for the interview and best contact information, respondent's preferred language and time of day for interview completion. The RC emailed or faxed this information directly to KKI using a secure transmission. The DCC did not see this paperwork as it included personal protected health information.

The KKI interviewers were flexible with the caregiver availability and worked to set up a time that was convenient, including evenings and weekends. A Spanish-speaking interviewer was available with some advanced planning and paid on a per-interview basis. KKI attempted to complete all interviews during a two-week window before and after the anniversary date. Even if the KKI interviewers did not successfully complete the interview at 3 months, they attempted the 12-month interview. The completed VABS-II was sent to the DCC where the data were entered into an electronic database.

Participants

Of the 624 children enrolled in the THAPCA trials, 251 children survived to 12 months. Of those, 242 had completed VABS-II data at 3 months and 239 had VABS-II data at 12 months. For each participant, call attempts were recorded on a de-identified call log. Of those with VABS-II data, 240/242 also had call logs at 3 months and 237/239 had call logs at 12 months. See flow diagram for details (Figure 1).

Participants' Characteristics

Participants' characteristics included age, sex, ethnicity, race, and household income. Pre-CA family functioning was measured using the General Functioning Scale of the Family Assessment Device (scored 0–4; 2 indicate abnormal functioning) (9). Post-CA functioning was rated at hospital discharge using the Pediatric Cerebral Performance Category (PCPC) provided a measure of neurological functioning and the Pediatric Overall Performance Category (POPC) provided a measure overall health (including neurological functioning) (10,11).

Telephone Call Characteristics

Telephone call characteristics were not included in the original THAPCA database but abstracted from the call logs after study completion to identify the number of days with attempted calls required to successfully complete a 3- or 12-month VABS-II, respondent's relationship to the participant, the timing of the completed calls, and language in which it was completed. The abstracted data were entered into a new database that was linked to the original THAPCA database, which included the participant's demographics and confirmed VABS-II completion dates.

Over the course of the THAPCA trials, the call attempts were documented with varying levels of detail. For purposes of this study, each date recorded on a participant's call log was coded as one day with attempted calls. Details such as "tried twice" (which were not consistently documented) were not considered if documented on the same day.

Advising Sites on Follow-up and Maintaining Site Engagement

To identify advice provided to site teams on how to reach caregivers, as well as methods to maintain site engagement over the years, we reviewed materials from the protocol, manual of operations, study training presentations, site newsletters, and minutes from monthly study team and executive committee meetings. We also reviewed the forums where the ongoing follow-up rate was regularly conveyed to study teams and other stakeholders.

Data Analysis

Characteristics of follow-up telephone calls and participant demographics were summarized using descriptive statistics. Demographics were compared between those with and without 3-month and 12-month VABS-II completion using *t*-tests for continuous variables, Wilcoxon rank sum tests for POPC and PCPC variables, and Fisher's exact test for categorical variables. All analyses were performed using SAS software, version 9.4 (SAS Institute).

RESULTS

Demographics

Table 1 depicts the characteristics of the 251 survivors at 12-months post-CA. Of the 251 survivors, 239 (95%) had a completed 12-month VABS-II (THAPCA-OH = 94/96 (98%); THAPCA-IH = 145/155 (94%). There were no significant differences between those with and without completed 12-month VABS-II based on age, race and ethnicity, family income, or participant's medical complexity (POPC/PCPC) at hospital discharge.

Interim (3-month) VABS-II data were collected for 242/251 (96%). Similar to the 12-month data, there were no significant differences between those with and without completed 3-month VABS-II based on age, race and ethnicity, family income, or participant's medical complexity (POPC/PCPC) at hospital discharge.

Of the families who completed the 3-month VABS-II, 96% completed the 12-month VABS-II as well. (3-month post-CA data not shown).

The VABS-II completion rate varied by study year. Years 1 (33 of 34 eligible), 2 (54 of 55 eligible), and 3 (71 of 73 eligible) had VABS-II completion rates of 97%, 98% and 97%, respectively. Completion rates were 92% in Year 4 (34/37) and 86% in Year 5 (30/35). The final year (Year 6) of the study had a 100% (17/17) completion rate, though relative to the other years, fewer participants were eligible for follow-up in that year.

Description of Telephone Call Characteristics

For those with completed VABS-II and available call logs (240 at 3 months, 237 at 12 months), key characteristics of the calls are presented in Table 2. At both 3 and 12 months, the respondents were predominately mothers followed by fathers. In more than 80% of cases, at least two days with attempted calls were needed to connect with the respondent and complete the VABS-II. With a maximum of 10 days with attempted calls, 95% of the successful calls were completed. Number of days with attempted calls were similar at 3 and 12 months.

At both 3 and 12 months, about 20% of calls were completed outside normal business hours for the KKI interviewer (Eastern Time zone). The majority of those completed outside of normal business hours were completed on the weekdays. A Spanish-speaking interviewer conducted 6% of the completed calls. At 3-months post arrest, 30% of children resided in facilities other than their home (e.g., hospital, in-patient rehabilitation unit, chronic care or skilled nursing facility or other). By 12-months post-CA, only 9% did not reside in a home setting.

Of the 9 children without completed VABS-II interviews at 3 months, the primary sites were unable to make contact with caregivers for 1 (11%). Call logs were unavailable for one additional child. Of the 7 remaining children, 2–5 call attempts were made to caregivers of 1 (14%), 6–10 call attempts were made to caregivers of 3 (43%), and 11–19 call attempts were made to 3 (43%). Of the 12 children without completed VABS-II interviews at 12 months, the primary sites were unable to make contact with caregivers for 2 (17%). Call logs were unavailable for two additional children. Of the 8 remaining children, 6–10 call attempts were made to caregivers of 4 (50%), 11–19 call attempts were made to 1 (13%), and 20 or more attempts were made to 3 (38%).

Strategies Employed for Primary Outcome Completion

Review of THAPCA trial documents found that throughout the life cycle of the THAPCA trials, a number of strategies were employed to promote telephone follow-up completion at 3- and 12- months post CA. These strategies are summarized in Supplemental Table 1.

During initial training, the study PIs created context for the site teams about the potential impact of the trial results on the care of critically ill pediatric patients, the primary outcome's importance, and consequences of losing enrolled participants to follow-up. Mandatory in-person retraining meetings were held to re-educate team on study procedures, maintain protocol fidelity and disseminate strategies to maximize follow-up. During the study enrollment period, the DCC and KKI staff had ongoing communication with the site teams, including monthly telephone calls and periodic webinars where RCs could openly seek and give advice on finding hard-to-reach participants. The KKI interviewer joined these

calls to discuss participants with upcoming follow-ups whose contact information was still needed. In addition, there were monthly site PI meetings and Executive committee meetings that carefully tracked enrollment and follow up rates.

To facilitate follow-up data collection at 2- and 11- months, the site RCs were asked to contact families to confirm the necessary information (i.e. vital status, preferred time of day for interview completion) and then send this information to KKI for surviving participants. To improve site engagement at follow-up, two key strategies were employed: electronic reminders and financial reimbursement. The DCC sent automated queries to the study teams at 2- and 11- months reminding them of each participant's upcoming follow-up. In addition to the reminders, site study teams were aware that stipend milestone payments for follow-up were not made if a participant was lost to follow-up. Site teams were diligent about collecting participant phone numbers, alternate phone numbers, information of extended families, etc. and following-up with families when KKI could not reach them. Also, to maximize accountability, the DCC regularly informed all site teams, along with the THAPCA Executive Committee, of the ongoing primary outcome rate and openly discussed strategies for improvement, if the rate declined in a given quarter.

To help maintain enthusiasm throughout the trial, the DCC regularly recognized the site teams for a "job well done" with awards certificates or handwritten thank-you notes. This strategy was particularly used after a hard-to-reach patient was found and the VABS-II was completed. More extensive "awards" ceremonies were made during annual in-person trainings or via webinar.

DISCUSSION

In this paper, we report on the telephone interview completion rate in 12-month survivors of CA enrolled in the THAPCA trials, identify the key characteristics of the completed follow-up interviews at both 3- and 12-months post-CA, and describe strategies employed to promote follow-up. A number of characteristics may have contributed to our high completion rate at both follow-up time points, including centralized collection of the primary outcome measure via telephone, flexibility in frequency and timing of calls, and type of individuals used as a respondent. Strategies used included emphasizing the relationship between the study team and the participants, ongoing communication between study team members across sites and over time, reimbursement to sites based on completion of primary outcome, and intensive intervention to promote engagement during the final year of the study.

While dropout rates can be as high as 30% during clinical trials (12), in the THAPCA trials, the primary outcome data (completed telephone interview) were successfully obtained for almost all survivors (96% at 3 months and 95% at 12 months). One potential reason for drop-out in similar studies may be the substantial family burden due to caring for a child with a high level of disability and complex medical issues. Caregivers of children enrolled in the THAPCA trials reported a high level of family burden in the first year after CA (13,14). Importantly, despite high family burden in this cohort, the 12-month follow-up rate was very high.

In cohorts with high caregiver burden, use of telephone follow-up, rather than onsite follow-up for collection of the primary outcome, likely contributed to the lack of demographic differences between those who completed and those who did not complete the VABS-II interview. In the THAPCA trials, rates of successful follow-up for secondary outcomes, which were collected during onsite examinations at 12 months, were lower than the telephone interview follow-up rates. (82% for neuropsychological and 80% for neurological follow-up) (15, 16).

Use of a dedicated interviewer, who had the time to make multiple telephone calls and the flexibility to accommodate the times that worked best for respondents, also likely contributed to the high follow-up rate. When examining the key characteristics of the days with attempted calls at 3 and 12 months, we found that few interviews were completed during the first day of an attempted call (18%) whereas almost all interviews (95%) were completed by the 10th day of an attempted call. Another key aspect to our high follow-up rates was the availability of the interviewer to complete interviews outside of business hours; 20% of interviews were completed outside of business hours during weekdays, or on the weekends. In future trial designs that involve telephone follow-up, interviewers should have flexible, protected time to be available on the evenings and weekends to accommodate families and protocols should include the use of multiple calls.

Defining potential interview respondents broadly (a relative or healthcare provider who knew the child well) was also an important strategy in THAPCA. While it could be argued that requiring the same respondent to complete the VABS-II interview at each time point would minimize error variance, restricting measurement in this way would have likely substantially decreased the study response rate. Moreover, limiting respondents to only parents or guardians also had the potential to be overly restrictive. In a small minority of THAPCA cases (9% at 3 months, 10% at 12 months), a relative other than a parent or healthcare provider completed the interview. While only 3% of our respondents were healthcare providers at 3 and 12 months, it is important to note that a substantial minority of participants were not living in a home setting at 3 (30%) and 12 (9%) months. Using a relative other than a parent or a healthcare provider as a potential respondent may be particularly important in similar studies with children with complex medical needs who reside outside of the home.

While telephone follow-up appeared to be convenient for most families, in future studies, there may be more efficient approaches to implement contemporary technology to set up outcome measures, such as through use of online assessment instruments accessed with a computer or smart phone. These methods would allow caregivers to complete the survey at the time that is most convenient for them. Results obtained from these measures, however, may bias families with limited access to computers or smart phones or limited experience using these devices (17). Therefore, trials using telephone interview (or giving respondents the option of either telephone or online assessments) may be preferred, because telephones are available to almost all families regardless of familiarity with and availability of technology.

Multiple strategies among the research teams were employed to promote successful collection of follow-up data. The relationship between the research team and participants' families, likely contributed to the high follow-up rate in THAPCA. Upon enrollment, the targeted temperature management intervention was administered for five days (120 hours). There was the potential for frequent visits to the bedside to check the participant's cooling equipment and temperature. The research staff also continued to follow the participant's hospital course until discharge, and reinforced with the parents the upcoming 3- and 12-months telephone calls. KKI and the DCC also relied on study team members, including the site PI when appropriate, to reach out to families who were difficult to contact for follow-up interviews.

In future studies, researchers may wish to connect with families of participants via social media as a strategy to stay connected and minimize loss to follow-up. Given that social media channels are not confidential, these types of connections should ensure patients' privacy is not violated and personal information cannot be identified (18). Possible strategies include creating a study specific forum on multiple social media platforms where study updates, relevant photos of the lab equipment/environment, and related news and publications can be shared with participant families and others who choose to connect.

Another important strategy was utilizing peer advice among site RCs. While the DCC and KKI could discuss in theory how to contact families successfully, the site RCs could give each other "real world" advice regarding contacting strategies. They were encouraged to share successful strategies during training meetings or on monthly calls. The importance of each and every follow-up was regularly communicated to the sites. When necessary, the DCC and KKI partnered with the sites to creatively work through challenges on a participant-by-participant basis. For example, for one family who did not own a phone for cultural reasons, the site RC coordinated a call with KKI immediately following a clinic visit at the hospital.

Specific strategies were also necessary to promote site engagement over the course of this multi-year study. The 12-month follow-up rate varied by year with a reduction in completed interviews during the later years of the study. KKI and DCC staff had weekly telephone calls with each other to closely monitor upcoming follow-ups and hosted calls with only those sites who had upcoming follow-ups. Maintaining engagement was particularly challenging in the final study stages when enrollment had ended, and study teams had other demands on their time. By the final year, some site personnel had been working on the study for six years and possible "study fatigue" had set in. The KKI and DCC staff attempted to keep the THAPCA follow-ups a priority for the site teams by providing intensive intervention (i.e. group calls with only those sites who had remaining 12-month interviews and individual calls to site teams).

Study limitations include inability to examine any clear causal relationships between characteristics of completed interviews, strategies implicated, and follow-up rate. Additionally, a clear definition of a "call attempt" was not originally defined in the protocol. Therefore, based on available data, we defined call attempts as "days with attempted calls" which may not be the exact number of attempted calls and may be an underestimation. Also,

information is not available about additional strategies that the study teams may have used at their sites to retain participants' families to maintain study engagement.

CONCLUSION

Using telephone interviews to successfully collect detailed neurobehavioral outcomes about children following CA is feasible and advantageous. Important strategies to promote successful telephone follow-up include availability of the telephone interviewer to make multiple calls at times convenient for families, using a range of respondents, ongoing engagement of and communication with the site teams, and including site reimbursement based on participant milestones.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1.
Flow diagram for completed Vineland Adaptive Behavior Scale – Second Edition (VABS-II)
interviews and available call logs

Table 1:

Characteristics of Month 12 Survivors by Month 12 VABS-II Completion

Characteristic	Month 12 VABS-II Completed		
	Overall (N = 251)	Yes (N = 239)	No (N = 12)
Age at Randomization (years): Mean (SD)	4.5 (5.63)	4.5 (5.56)	4.8 (7.12)
Ethnicity			
Hispanic or Latino	51 (20%)	49 (21%)	2 (17%)
Not Hispanic or Latino	190 (76%)	181 (76%)	9 (75%)
Stated as Unknown	10 (4%)	9 (4%)	1 (8%)
Male	157 (63%)	149 (62%)	8 (67%)
Race			
American Indian or Alaska Native	3 (1%)	3 (1%)	0 (0%)
Asian	7 (3%)	7 (3%)	0 (0%)
Black or African American	72 (29%)	67 (28%)	5 (42%)
White	141 (56%)	135 (56%)	6 (50%)
Other	8 (3%)	8 (3%)	0 (0%)
Unknown	20 (8%)	19 (8%)	1 (8%)
Study			
IH	155 (62%)	145 (61%)	10 (83%)
OH	96 (38%)	94 (39%)	2 (17%)
Annual household income of child's family			
Less than \$30,000	104 (41%)	98 (41%)	6 (50%)
\$30,000 to < \$50,000	42 (17%)	40 (17%)	2 (17%)
\$50,000 or more	75 (30%)	71 (30%)	4 (33%)
Stated as unknown	13 (5%)	13 (5%)	0 (0%)
Question not answered	17 (7%)	17 (7%)	0 (0%)
Average FAD score: Mean (SD) *	1.5 (0.43)	1.5 (0.43)	1.5 (0.34)
Hospital Discharge **			
POPC			
Good = 1	42 (17%)	40 (17%)	2 (17%)
Mild disability = 2	71 (28%)	69 (29%)	2 (17%)
Moderate disability = 3	54 (22%)	50 (21%)	4 (33%)
Severe disability = 4	52 (21%)	50 (21%)	2 (17%)
Coma or vegetative state = 5	31 (12%)	29 (12%)	2 (17%)
PCPC			
Normal = 1	68 (27%)	65 (27%)	3 (25%)
Mild disability = 2	64 (26%)	61 (26%)	3 (25%)
Moderate disability = 3	42 (17%)	40 (17%)	2 (17%)
Severe disability = 4	45 (18%)	43 (18%)	2 (17%)
Coma or vegetative state = 5	31 (12%)	29 (12%)	2 (17%)
Receiving supplemental oxygen	51 (20%)	50 (21%)	1 (8%)

Characteristic	Month 12 VABS-II Completed		
	Overall (N = 251)	Yes (N = 239)	No (N = 12)
Tracheostomy present	53 (21%)	52 (22%)	1 (8%)
Mechanical Ventilation	36 (14%)	35 (15%)	1 (8%)
Gastric or small bowel feeding tube	100 (40%)	96 (40%)	4 (33%)

IH = In-Hospital, OH = Out-of-Hospital, FAD = Family Assessment Device, POPC = Pediatric Overall Performance Category, PCPC = Pediatric Cerebral Performance Category.

* Average FAD score missing for 5 patients.

** Hospital discharge information missing for one patient who was not yet discharged at 12 months.

*** P>0.05 for all comparisons between the two groups.

Table 2.**Key Characteristics of Telephone Calls at 3 and 12 months**

Characteristic	Completed Month 3 VABS-II (N = 240)	Completed Month 12 VABS-II (N = 237)
Respondent Relation		
Mother	195 (81%)	183 (77%)
Father	24 (10%)	30 (13%)
Other relative	13 (5%)	17 (7%)
Healthcare provider	8 (3%)	7 (3%)
Number of days attempts were made		
Median (Q1, Q3)	3.0 (2.0, 5.0)	3.0 (2.0, 4.0)
1	44 (18%)	41 (17%)
2–5	150 (63%)	154 (65%)
6–10	33 (14%)	31 (13%)
11–19	11 (5%)	10 (4%)
20+	2 (1%)	1 (0%)
KKI Completion Time		
Weekday between 9–5	187 (78%)	196 (83%)
Weekday outside 9–5	41 (17%)	33 (14%)
Weekend	12 (5%)	8 (3%)
Spanish-speaking interviewer	15 (6%)	14 (6%)
Primary location of patient over previous month		
Home or foster care	167 (70%)	215 (91%)
Acute care hospital	52 (22%)	11 (5%)
Acute inpatient rehabilitation unit	14 (6%)	1 (0%)
Chronic care or skilled nursing facility	6 (3%)	8 (3%)
Other	1 (0%)	2 (1%)
UK Site	6 (3%)	6 (3%)

VABS-II = Vineland Adaptive Behavior Scale, Second Edition, KKI = Kennedy Krieger Institute.

Table excludes data for four completed calls (2 at 3 months, 2 at 12 months) due to missing call logs.