

PROGRAM REPORT

ALMOST HOME KIDS:

A Unique Hospital-to-Home Transitional Care Model for Children with Technology Dependency

Sarah A. Sobotka, MD, MSc,^a Emma Lynch, MPH,^a Wendy Tian, BA,^b Michael E. Msall, MD,^a Monica E. Peek, MD MPH^c

ABSTRACT

BACKGROUND: Children with medical technology dependency often remain hospitalized for long periods while preparing to transition home. To our knowledge, no comprehensive reports of alternative locations for hospital-to-home transition have been described in the literature.

OBJECTIVES: We present a comprehensive report and evaluation of patient and family outcomes before and after admission to Almost Home Kids (AHK), a hospital-to-home transitional care center, which provides a home-like setting for parent training, care coordination, and case management for children with medical technology dependency.

OUTCOMES: Descriptive statistics were used to characterize the children and their parents during the transitional care admission and following discharge. Parents were given questionnaires which assessed their community support, knowledge and skills with medical technology management, physical and mental health, and discharge readiness. After admission to the AHK transition program as compared to before, children had significantly increased access to primary care and home nursing, more referrals to Early Intervention and more received speech therapy services. Parents reported increased comfort with responding to ventilator alarms, checking back-up ventilators, and managing feeding tubes.

CONCLUSIONS: For children with technology dependency, enrollment in the AHK hospital-to-home transitional care program may effectively deliver parent training and broaden the child's access to community health, rehabilitation and nursing resources.

^aSection of Developmental and Behavioral Pediatrics, University of Chicago, Chicago, IL; ^bRush Medical College, Chicago, IL; ^cSection of General Internal Medicine, Department of Medicine University of Chicago, Chicago, IL

INTRODUCTION

Children living with technology dependence, needing both a medical device to compensate for the loss of a vital body function and substantial nursing care to avert death or further disability,¹ are increasing in pediatric populations²⁻⁵ and are overrepresented in hospitalizations.^{6,7} The discharge process for this population is complicated because of elaborate care coordination and training needs, and frequent delays in staffing home nursing. Before children with new technology dependence can be discharged, children must be medically stable and linked to community resources, their parents trained, and their home equipped to sustain the technology.^{8,9} This requires an interdisciplinary team which may include clinicians, case managers, and respiratory, speech, feeding, occupational, and physical therapists.^{10,11} Often the greatest obstacles to hospital discharge are non-medical, e.g. approval for home care funding, home nursing, and social issues.^{12,13} Most parent training programs are time-intensive and delivered in the context of the child's inpatient hospital stay.^{14,15} Additionally, there is evidence that home nursing shortages are a national impediment to discharge.¹⁶

Thus, the hospitalizations when a medical technology is first placed often require lengths of stay (LOS) of many months in order to prepare families to transition home. For example, children undergoing tracheotomy are reported to have with median hospitalization LOS between 1.5 to 9.6 months.^{17,18}

Long hospital LOS can also be detrimental to child neurodevelopment and family well-being. In a study of children with congenital heart disease, longer LOS after heart surgery seemed to be potentially associated with worse cognitive outcomes after controlling for demographic and surgical outcome variables.¹⁹ After PICU hospitalizations, parents of children have been found to have significantly increased stress,²⁰ with a quarter experiencing Post Traumatic Stress Disorder,²¹ and many experiencing depression and anxiety.^{22,23}

Therefore, it is imperative that health systems consider alternatives that minimize hospital LOS, especially for neurodevelopmentally vulnerable patients with technology dependence. Although interventions have been described which standardize inpatient discharge practices for teams caring for children with home mechanical ventilation,²⁴ there is a dearth of

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evidence-based alternatives to the hospital for transition planning and training. The objective of this paper is to describe an innovative community-based model for hospital-to-home transition and to evaluate child and parent outcomes assessing knowledge, technical skills, and utilization of community-based health services.

PROGRAM DESCRIPTION

ALMOST HOME KIDS (AHK): AHK was originally established in 1999 by two mothers who saw the need for a respite care center for children with medical

technology dependence. AHK now has three free-standing centers that provide hospital-to-home transition care and respite care for children. (Figure 1) The programs aim to empower families to care for complex children at home and family training is a core focus. Over time, many families who complete hospital-to-home transitional care return to AHK for respite care.²⁵

AHK is a unique model that is different from a hospital, long term care facility or rehabilitation center. The hospital-to-home transitional care program at AHK is specifically for children who are medically ready for discharge, but cannot go home



Figure 1. Clockwise from upper right: Nurse training parents; Almost Home Kids - Chicago suburban site; Therapists work with a young child; Almost Home Kids - downtown Chicago site.

due to social and/or other resource obstacles. Hospital discharge planners, social workers, nurses and physicians refer eligible children to AHK transitional care by contacting the director of case management. AHK is designed to simulate a home, with brightly decorated bedrooms, a large kitchen, and several play areas for families to engage with their child and other families. This environment allows for families to learn and practice caring for their children in a home-like setting. Case managers, social workers, and nurses teach families the skills needed to care for their children when they transition home. Room pairings are by age or developmental stage and all children who are not on infectious isolation spend the majority of their time in common areas. There are two locations in the Chicagoland area, each with a 12-bed capacity, and in 2018 a third location opened in central Illinois. The centers serve children from all of the pediatric hospitals in the region. Although parents are unable to room-in with their children at the Naperville center, in the downtown Chicago location, parents and siblings can stay at a Ronald McDonald House located within the same building.

The focus of the AHK hospital-to-home transition program is parent training, which

consists of nurses providing bedside education on medical equipment and medication administration. Nursing staff teach parents to understand key drug interactions and how to troubleshoot equipment malfunctions. Before discharge, parents must demonstrate mastery of medical tasks. In between parent training sessions, children are transported to and from AHK for outpatient appointments, receive nursing support (as they would at home) and have access to an on-call physician or advanced practice nurse. Additionally, parents receive education from case management on resource coordination. This family-centered approach provides additional support for families as they learn to independently manage the medical care and become the central care coordinator for their child.

PROGRAM SUPPORT

FUNDING AND TEAM COMPOSITION:

AHK is funded by a combination of provider billing to insurance, grant funding, and private donations. Each site has a medical director and advanced practice nurse who round weekly on all patients. Case management and social work are available daily and skilled nurses support each patient with at most a 1:3 patient ratio. A full-time

child life specialist helps to craft developmental goals for each child, and Early Intervention (EI) services are provided at the center. A robust volunteer program infuses AHK with vibrant visitors and playmates for the children throughout their day.

OUTCOMES

A descriptive study was implemented consisting of children and their parents who participated in the AHK transitional care program between December 2013 and April 2016. For those parents who gave consent to participate in this research project, questionnaires were administered on admission, discharge, and in follow-up after discharge from the center.

PARTICIPANT RECRUITMENT: Parents of children admitted to AHK were eligible for study inclusion if: 1. Their child was dependent upon medical technology; 2. Parents were receiving first-time training at AHK on new medical technology they had never been home with, or new foster parents were receiving training on a foster child's existing medical technology; 3. The child was expected to transition to home. Additionally, parents/guardians must have had full custody of their children. The University of Chicago Institutional Review

Board (IRB) approved this study in November 2013, and the Department of Child and Family Services (DCFS) IRB approved it in May 2014. AHK staff invited eligible parents to participate. Consent was obtained from parents; no children were of age and developmental stage to provide assent. Parents received an incentive (\$20 gift card) for each questionnaire completed after AHK discharge.

MEASURES: Questionnaires included items from validated surveys, e.g. The National Survey of Children with Special Healthcare Needs.²⁶ For constructs without a previously validated measure, questionnaire items were developed and cognitively tested. Researchers consulted with senior nursing staff to determine appropriate questions to assess parents' mastery of medical technology management. Study participants were provided an iPad with a keyboard to complete the questionnaires, which were managed using Research Electronic Data Capture.²⁷ Each questionnaire took approximately 20 minutes.

Parent respondents were asked their relationship to the child; four relationship types were reported: mother, father, foster parent, and adoptive parent. Parents reported

household income in 12 categories which were dichotomized into <\$50,000 versus at least \$50,000 on median distribution for the analysis. Parents were asked about their current work status with close-coded options being full-time, part-time or not working.

Parents provided information about their child. Maternal answers were used for child characteristics when two parents responded. Age was reported in months and grouped into three categories: <4 months, 4-35 months, and 3-14 years. Race was defined by the question, "What is your child's race? (check all that apply)." Ethnicity was defined by, "Is your child of Hispanic, Latino, or Spanish origin?" The U.S. federal government and the National Academy of Medicine recommend self-report for identification of patient race/ethnicity.²⁸ Parents were asked two questions about the home environment: number of children and primary language spoken.

Administrative data from the AHK center was used to compare data on non-participants in aggregate.

Parents reported their child's medical technologies (e.g. feeding tubes, tracheostomies, and ventilators) from

a list generated in consultation with AHK nursing supervisors.

All parents were asked, "Were you trained to use the same equipment you will use at home?" Parents were also asked questions specific to their child's medical technologies. Parents of children with a ventilator were asked if they had received CPR training, how comfortable they felt responding to ventilator alarms, if they knew ventilator settings, and if they could perform a back-up ventilator check. Parents of children with tracheostomies were asked if they had ever changed a tracheostomy with a second caregiver, and if they had ever changed one independently. Parents of children with feeding tubes were asked about their comfort level cleaning and changing a feeding tube and using a feeding pump. Questions about parental comfort level had close-coded Likert-type response options ranging from "very comfortable" to "very uncomfortable," which were dichotomized in the analysis to "very comfortable" versus less, based on response distribution.

Healthcare access was assessed at each of the three data collection time points in order to measure

changes in service referral and utilization over time. Parents provided information about the number of home nursing hours they received and if they had a place for usual medical care. All parents were asked about therapy services. For children under the age of three, these services were provided through the EI program.

Two questions, adapted from the Medical Outcomes Study,²⁹ were asked about self-reported parent health: “In general, how would you rate your own current physical health?” “In general, how would you rate your own current mental health?” Responses were collapsed into three categories: Excellent, Very Good/Good, and Fair/Poor, based on response distribution frequencies.

STATISTICAL METHODS: Descriptive statistics were used to characterize the children admitted to AHK and their parents. Questionnaire response items for child and parent outcomes were compared using Chi-squared tests of proportions, McNemar’s test or a generalized estimating equation (GEE) logistic regression model that accounted for the correlation between multiple observations per patient. Statistical analyses were completed with STATA/SE 14 (Stata Corp, College Station, TX).

Statistical significance was defined as a two-tailed p-value less than 0.05.

RESULTS: Seventy families met the medical inclusion criteria. (Figure 2) Six families had DCFS involvement without full DCFS custody and therefore were determined to be ineligible. Forty-three parents enrolled from a total of 32 families. Twenty-three parents declined participation and nine families were missed recruitment opportunities. A number of participants had brief acute care hospital visits for medical illnesses during their AHK transitional stay, however completed training at AHK before discharge to home. One participant transferred to a hospital before discharge

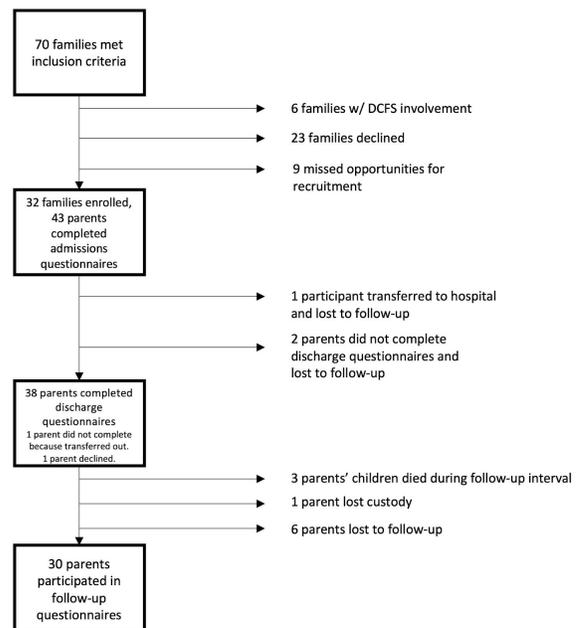


Figure 2. Recruitment and Retention Flow Chart

home and was lost to follow-up. Two parents did not complete discharge questionnaires and were lost to follow-up. Thirty-eight discharge questionnaires were analyzed. Four parents were not contacted for follow-up, three because their child had passed away before the follow-up interval and one because the parent had lost custody. Six parents were lost to follow-up after AHK discharge. Thirty parents completed follow-up questionnaires an average of 3.6 months after AHK discharge. There were no statistically significant differences between non-participant and participant children regarding age, gender, ethnicity, and the frequency of medical equipment. (Table 1) However, non-participants were more likely than

participants to have lower household incomes and be from non-primary English-speaking households.

In regard to the duration of hospital and AHK stays, before AHK, one-third of participating families had acute care stays less than two months, half of families had stays of 2-6 months, and 15% had stays of greater than six months. The average length of stay at AHK was 101 days with a median (range) length of 74 (12-251) days.

Parents were primarily mothers (53%); 26% were foster or adoptive parents. Children ranged between 4 months and 14 years old, the majority of which were under 3 years old (82%). Thirty-one percent were Non-Hispanic White, 31% Non-Hispanic Black, and 28% Hispanic. Nearly half of respondents came from households making less than \$50,000 per year.

Ninety-one percent of children had feeding tubes, 48% had tracheostomies, and 33% required ventilators. Thirty percent of children had both a feeding tube and a ventilator.

Overall, parents reported increased connectedness to community resources: 84% of parents reported having

Characteristic	Participants (N=32)	Non-participants (N = 38)	P-value*
Child Characteristics			
Age of child			0.08
< 4 months	7 (22)	3 (8)	
4-35 months	19 (60)	23 (61)	
3-14 years	6 (19)	12 (31)	
Male child	20 (63)	22 (58)	0.62
Race/Ethnicity of Child (N=31)			
			0.78
Non-Hispanic White	10 (32)	10 (26)	
Non-Hispanic Black	10 (32)	11 (29)	
Hispanic	9 (29)	15 (39)	
Mixed/Other	2 (6)	2 (5)	
Household Income* (N=31)			
			<0.001
< \$50,000	15 (48)	34 (92)	
≥ \$50,000	16 (52)	3 (8)	
Medical Equipment			
Feeding tube	29 (91)	36 (97)	0.25
Tracheostomy	16 (50)	21 (57)	0.49
Ventilator	11 (34)	13 (35)	0.87
Home Characteristics			
Number of children in the home			0.66
1-2 children	19 (61)	23 (68)	
3 or more	12 (39)	11 (32)	
Primary language not English	4 (13)	12 (32)	0.05
Parent Characteristics (N=43)			
Relationship to child			
Mother	23 (53)		
Father	9 (21)		
Foster/Adoptive Parent	11 (26)		
Work Status (N=42)			
Full-time or part-time	22 (52)		
Not currently working	20 (48)		

*P-values generated using Chi-square tests. Wilcoxon rank-sum test used for age of child comparison
 *One response missing for each of the discharge and admission questionnaires (N=31 and N=36, respectively)

Table 1. Characteristics of Parents (N=43) & Children (N=32)

	Admission (%)	Discharge (%)	Follow-Up (%)	P-value
Connection to Community Resources (N=42)				
Has usual place for medical care	64	84	83	0.02
Early Intervention (EI) if child under 3 years (N=36)				
Initial Referral to EI	61	93	100	<0.001
Receiving Physical Therapy	28	44	42	0.17
Receiving Occupational Therapy	14	33	17	0.10
Receiving Speech Therapy	19	39	42	0.05
Receiving Developmental Therapy	17	31	39	0.16
Receiving Feeding Therapy	6	8	17	0.07
Receiving Nutritional Therapy	3	6	19	0.07
Home nursing hours received per week (N=32)				
None/Unknown	84	43	42	<0.001
1-24 hours	3	3	4	
25-72 hours	9	27	21	
> 72 hours	3	27	33	

*p-values generated using GEE poisson regression in order to compare [trend] over time. Nursing hours compared using mixed-effects ordinal logistic regression. Statistical significance defined as two-tailed p-value <0.05

Table 2. Community Resources after AHK Transitional Care Stay (%)

a usual place for their child's medical care (versus only 64% at admission), and this was sustained at follow-up (83%) (p=0.02). (Table 2) For the population under age three, after discharge from AHK significantly more were referred to EI and receiving speech therapy than prior to discharge (p<0.001 and p<0.05, respectively). Increased receipt of feeding and nutritional therapies showed a trend toward significance (p=0.07).

There was also a meaningful increase in the number of approved home nursing hours. On discharge, fifty-four percent of parents reported having at least 25 nursing hours weekly for their child, versus only 13% on admission (p<0.001). Nursing care was sustained in follow-up.

There were improvements in parent training on medical equipment during the AHK admission.

Table 3. Impact of AHK Transitional Care (%) - Parent Outcomes

(Table 3) Nearly all (95%) of parents report being trained on the same equipment they would use at home compared to 58% on AHK admission (p<0.001). Parents of children with tracheostomies and ventilators were all CPR trained and significantly more parents reported feeling very comfortable responding to alarms and performing back-up ventilator checks (p=0.02 and p=0.01, respectively). Parents of children with feeding tubes reported increased comfort with cleaning and changing the tubes (p=0.007). Technology management skills were sustained during follow-up. Parent-reported physical and mental health ratings were unchanged over time.

PROGRAM SUMMARY

This program report provides preliminary evidence that AHK, an alternative to the

hospital during hospital-to-home transition, is an effective program for parents to develop the necessary skills for managing their complex children in the home and for care coordination to arrange essential home services before discharge. Additionally, our follow-up data suggest that parent skills and community services are maintained. Due to the descriptive nature of this cohort, it is not known to what extent parent skills in follow-up reflect one's natural mastery of skills over time, so we are cautious to over interpret follow-up results as a function of AHK's role in the transition. However, the continued access to community resources identifies the strong case management that AHK transition provided for these families.

Children staying at AHK would have likely spent several additional months in the hospital at higher financial cost without the availability of this program.³⁰ AHK estimates their program costs per patient bed day by determining the program revenue minus the program expense divided by census bed days. Caring for the most complicated patients, those dependent upon mechanical ventilation who require intensive skilled nursing 6-8 hours per day, is estimated to cost approximately \$1,250/day. Patients with less technology (e.g. a feeding tube) cost the center approximately \$850/day. For

children with ventilators, this compares to an estimated \$2,052 for hospital days on a pediatric ventilator unit and \$3,565 for hospital days in intensive care units.³¹

Over the course of a few months, parents describe an increase in skills and comfort managing medical technology. The graduates of this program are more connected with primary care, rehabilitative therapy services, and home nursing than before their transition.

Our data should be considered in light of important limitations. First, our response rate around 50% of eligible families was not ideal for generalizing conclusions across this population. Parents of children with medical technology dependence, particularly in the challenging time of initial transition to home, are spread thin between obligations. We suspect the same stressors that have been reported to challenge parents' ability to complete parent training³² also limited our ability to recruit families. Using administrative data from the AHK center, we note that participant and non-participant families were similar in regard to many relevant child characteristics (age, gender, ethnicity, and medical equipment), however participant families were more affluent. Poverty certainly

impacts a family's ability to care for a child with medical complexity. Therefore, our results may not be completely generalizable to populations with greater socioeconomic adversity, although this response pattern is common for research conducted with underserved populations.^{33,34} Second, the data presented in this paper reflect the immediate hospital-to-home transition period. Longer follow-up studies are needed and we hope to provide data from this center over time when available.

CONCLUSION

This preliminary study of an innovative hospital-to-home transitional care model, which prioritizes parent training, care coordination, and accessing community resources, shows promise as a family-centered alternative to prolonged

inpatient hospitalizations. Ongoing investigation will determine the model's long-term impacts on child health, community participation, family well-being, and health care costs.

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CORRESPONDENCE: Sarah A. Sobotka, MD, MSc, Section of Developmental and Behavioral Pediatrics, University of Chicago, 950 E. 61st Street, SSC Suite 207, Chicago, IL 60637. Email: ssobotka@peds.bsd.uchicago.edu.

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IMAGES AND TABLES



Figure 1. Clockwise from upper right: Nurse training parents; Almost Home Kids - Chicago suburban site; Therapists work with a young child; Almost Home Kids - downtown Chicago site.

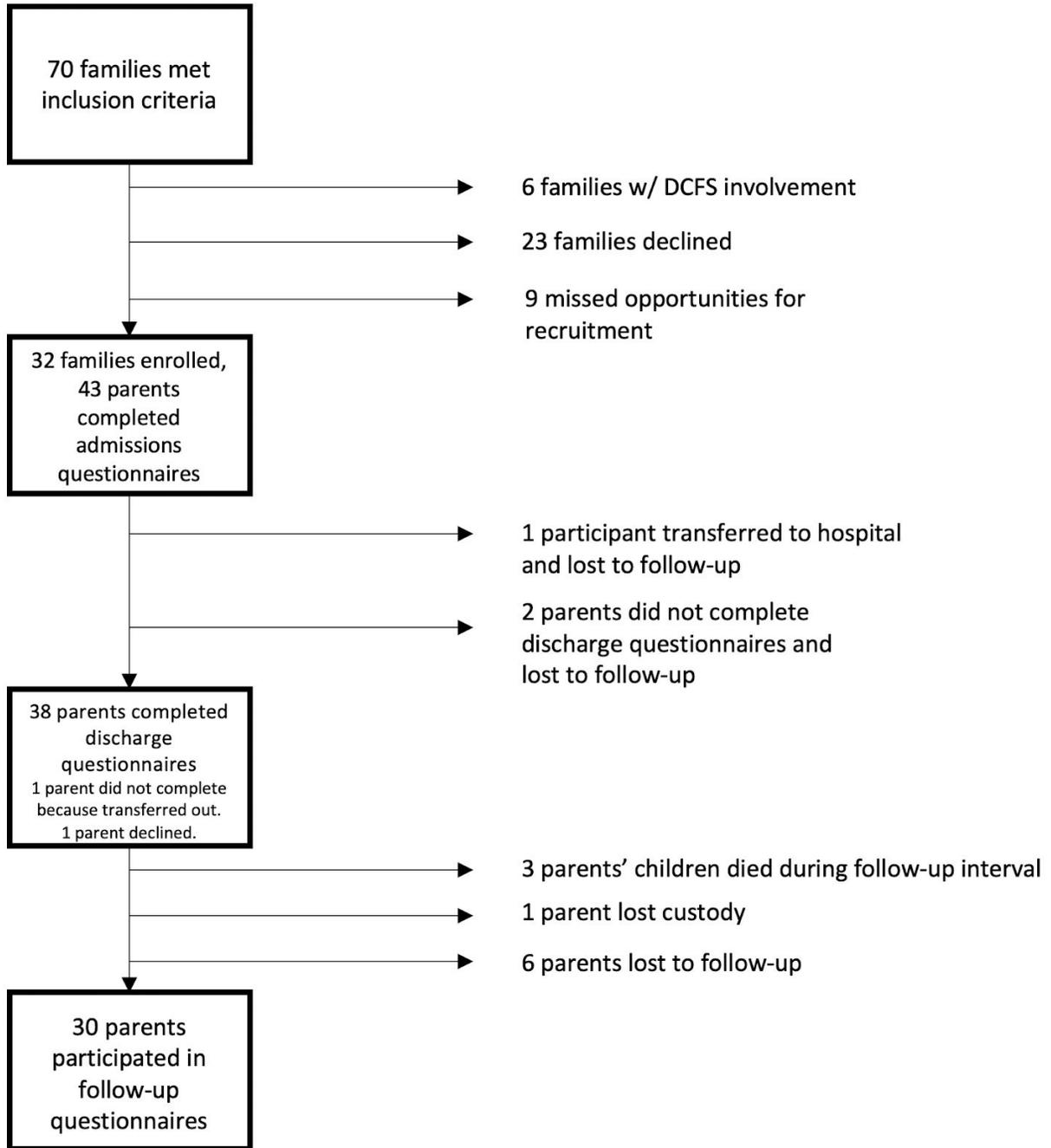


Figure 2. Recruitment and Retention Flow Chart

	Participants (N=32)	Non-participants (N = 38)	P-value*
Characteristic			
Child Characteristics			
Age of child			0.08
< 4 months	7 (22)	3 (8)	
4-35 months	19 (60)	23 (61)	
3-14 years	6 (19)	12 (31)	
Male child	20 (63)	22 (58)	0.62
Race/Ethnicity of Child (N=31)			
			0.78
Non-Hispanic White	10 (32)	10 (26)	
Non-Hispanic Black	10 (32)	11 (29)	
Hispanic	9 (29)	15 (39)	
Mixed/Other	2 (6)	2 (5)	
Household Income^o (N=31)			
			<0.001
< \$50,000	15 (48)	34 (92)	
≥ \$50,000	16 (52)	3 (8)	
Medical Equipment			
Feeding tube	29 (91)	36 (97)	0.25
Tracheostomy	16 (50)	21 (57)	0.49
Ventilator	11 (34)	13 (35)	0.87
Home Characteristics			
Number of children in the home			0.66
1-2 children	19 (61)	23 (68)	
3 or more	12 (39)	11 (32)	
Primary language not English	4 (13)	12 (32)	0.05
Parent Characteristics (N=43)			
Relationship to child			
Mother	23 (53)		
Father	9 (21)		
Foster/Adoptive Parent	11 (26)		
Work Status (N=42)			
Full-time or part-time	22 (52)		
Not currently working	20 (48)		

*p-values generated using Chi-square tests. Wilcoxon rank-sum test used for age of child comparison

^oOne response missing for each of the discharge and admission questionnaires (N=31 and N=36, respectively)

Table 1. Characteristics of Parents (N=43) & Children (N=32)

	Admission (%)	Discharge (%)	Follow-Up (%)	P-value*
Connection to Community Resources (N=42)				
Has usual place for medical care	64	84	83	0.02
Early Intervention (EI) if child under 3 years (N=36)				
Initial Referral to EI	61	93	100	<0.001
Receiving Physical Therapy	28	44	42	0.17
Receiving Occupational Therapy	14	33	17	0.10
Receiving Speech Therapy	19	39	42	0.05
Receiving Developmental Therapy	17	31	39	0.16
Receiving Feeding Therapy	6	8	17	0.07
Receiving Nutritional Therapy	3	6	19	0.07
Home nursing hours received per week (N=32)				<0.001
None/Unknown	84	43	42	
1-24 hours	3	3	4	
25-72 hours	9	27	21	
> 72 hours	3	27	33	

*p-values generated using GEE poisson regression in order to compare trend over time. Nursing hours compared using mixed-effects ordinal logistic regression. Statistical significance defined as two-tailed p-value <0.05

Table 2. Community Resources after AHK Transitional Care Stay (%)

Table 3. Impact of AHK Transitional Care (%)- Parent Outcomes



Complex Care Journal

Almost Home Kids: A Unique Hospital-To-Home Transitional Care Model for Children with Technology Dependency

Sarah A. Sobotka, MD, MSc, Emma Lynch, MPH, Wendy Tian, BA, Michael E. Msall, MD,
Monica E. Peek, MD MPH

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