WILEY | ISPAD

ORIGINAL ARTICLE

Home-based vs inpatient education for children newly diagnosed with type 1 diabetes

H. Clapin[1,2] | L. Hop[1] | E. Ritchie[1] | R. Jayabalan[1] | M. Evans[1,2] | K. Browne-Cooper[1] | S. Peter[3] | J. Vine[3] | T. W. Jones[1,2] | E. A. Davis[1,2]

[1]Department of Endocrinology and Diabetes, Princess Margaret Hospital for Children, Perth Australia

[2]Telethon Kids Institute, The University of Western Australia, Perth Australia

[3]Hospital in the Home, Princess Margaret Hospital for Children, Perth Australia

Correspondence
Helen Clapin, Department of Endocrinology and Diabetes, Princess Margaret Hospital for Children, GPO Box D184, Perth WA 6840, Australia.
Email: helen.clapin@health.wa.gov.au

Funding information
PMH Foundation; WA Department of Health; Paediatric Medicine Clinical Care Unit of PMH

Background: Initial management of children diagnosed with type 1 diabetes (T1D) varies worldwide with sparse high quality evidence regarding the impact of different models of care.

Aim: To compare the inpatient model of care with a hybrid home-based alternative, examining metabolic and psychosocial outcomes, diabetes knowledge, length of stay, and patient satisfaction.

Subjects and Methods: The study design was a randomized-controlled trial. Inclusion criteria were: newly diagnosed T1D, aged 3 to 16 years, living within approximately 1 hour of the hospital, English-speaking, access to transport, absence of significant medical or psychosocial comorbidity. Patients were randomized to standard care with a 5 to 6 day initial inpatient stay or discharge after 2 days for home-based management. All patients received practical skills training in the first 48 hours. The intervention group was visited twice/day by a nurse for 2 days to assist with injections, then a multi-disciplinary team made 3 home visits over 2 weeks to complete education. Patients were followed up for 12 months. Clinical outcomes included HbA1c, hypoglycemia, and diabetes-related readmissions. Surveys measured patient satisfaction, diabetes knowledge, family impact, and quality of life.

Results: Fifty patients were recruited, 25 to each group. There were no differences in medical or psychosocial outcomes or diabetes knowledge. Average length of admission was 1.9 days shorter for the intervention group. Families indicated that with hindsight, most would choose home- over hospital-based management.

Conclusions: With adequate support, children newly diagnosed with T1D can be safely managed at home following practical skills training.

KEYWORDS

ambulatory, education, pediatric, randomized-controlled trial, type 1 diabetes mellitus

1 | INTRODUCTION

Type 1 diabetes (T1D) is one of the most prevalent chronic diseases of childhood, occurring with increasing frequency in Australia[1] and around the world.[2] Since the 1990s, pediatric practices relating to children with new onset T1D have ranged from routine admission for 2 to 3 weeks in countries across Europe[3–5] and in Japan[6] to ambulatory care from diagnosis in centres in the UK,[7] US,[8,9] and Australia.[10] Some children require hospitalization for intravenous therapy to correct dehydration, electrolyte imbalance, and diabetic ketoacidosis (DKA) but the majority are clinically well at presentation. In addition

to being commenced on insulin therapy and stabilized, comprehensive education on practical and theoretical aspects of diabetes management is delivered in the period immediately following diagnosis.

Increasing cost pressure on health-care systems makes home-based management of children at diagnosis of T1D an attractive option, however, there is little evidence to support this practice and reviews have been inconclusive.[11,12] The definition of home management varies between studies, ranging from no hospital admission unless required for stabilization[13,14] to 2 to 3 days in hospital.[15] Some models incorporate nursing support in the home[13,15] while others require patients to attend hospital as outpatients for care and

education.[10,14] Retrospective studies have suggested that children with new onset T1D can be safely educated in a home or outpatient setting[9,14,16] however these studies rely on medical records and are biased by inherent differences between the comparison groups as patients selected for home care are often those more likely to succeed in diabetes management.[17] Hence randomization is an important factor in study design yet few randomized-controlled trials (RCTs) have been conducted. Findings from the 2 RCTs identified in the literature indicate possible advantages to home-based care in terms of medical[13] and psychosocial outcomes[15] but in both studies the home-based care group was assigned a dedicated diabetes nurse who by design, was more available to patients and families, spent more time on education, and provided more individualized learning. The protocol for a large RCT in the UK was published in 2011[18] but results are not yet available. To date, no randomized-controlled trials have been conducted in Australia.

Princess Margaret Hospital for Children (PMH) is the only pediatric referral and treatment centre for T1D in the state of Western Australia (WA) and manages more than 99% of children under 16 years diagnosed with T1D in the state,[1] approximately 35% of whom reside in rural and remote areas. On average, 120 children are diagnosed with T1D in WA each year and currently all are admitted at diagnosis, remaining in hospital for an average of 5 to 6 days. During this time the family receives 10 to 11 hours of intensive education from a diabetes nurse educator and dietitian, as well as a comprehensive social work assessment and support as required, while insulin therapy is instituted.

The aim of this study was to compare the inpatient education model for children newly diagnosed with T1D with a hybrid home-based alternative, in terms of (1) metabolic and psychosocial outcomes in the first year after diagnosis; (2) diabetes knowledge; (3) length of stay; and (4) patient satisfaction.

2 | METHODS

2.1 | Study design

A randomized-controlled trial (RCT) was conducted at PMH, with patients recruited consecutively from September 2012. Families of eligible patients were invited to participate and given 24 hours to make a decision. Consenting patients were randomized to either the control group (standard inpatient care and education) or the intervention group (discharge after 2 days for home-based management).

Inclusion criteria were: aged 3 to 16 years at diagnosis; living within the catchment area for the Hospital in the Home (HiTH) service approximately 1 hour from the hospital by car; English-speaking; able to access transport; assessed by the treating team to be medically and socially suitable for early discharge. Exclusion criteria were: DKA at initial presentation; complex family issues such as custody disputes.

All patients/families received practical skills training in the first 48 hours following diagnosis. Patients in the intervention group were then discharged and a HiTH nurse visited to supervise breakfast and dinner injections for the first 2 days at home. A multi-disciplinary team conducted 3 home visits during the next 2 weeks to complete initial education. The team consisted of a diabetes nurse educator accompanied by either a dietitian (2 visits) or a social worker (1 visit). Each visit was approximately 2 hours in duration.

The educational content and staff pool were identical for the intervention and control groups. Additional staff (FTE) employed to enable the trial included a coordinator (0.4) diabetes nurse educator (0.6), dietitian (0.4) and social worker (0.2). Staff were assigned depending on availability and for both groups, consistency of staff at the individual patient level was maintained where possible. As is standard practice at PMH, the importance of having 2 carers present for education sessions was emphasised for all participants.

All patients attended regular outpatient clinic appointments following the completion of the initial education.

Approval to conduct this study was obtained from the PMH Ethics Committee.

2.2 | Outcome measures

Clinical outcome measures were collected at diagnosis and then at 3-monthly intervals and included HbA1c (Ames DCA 2000; Bayer, Mishawaka, Indiana), hypoglycemic events, total daily insulin dose (TDD), and insulin regimen. Severe hypoglycemia was defined as an episode resulting in a convulsion or coma. Diabetes-related readmissions were ascertained from hospital records and chart review.

A patient satisfaction survey (Appendix) was completed by parents at 1 month post-diagnosis. It assessed satisfaction with medical care, education and support received overall and more specifically with aspects of the admission process, staff availability, support, education sessions, and discharge. It also measured parental confidence in managing diabetes and preference for home-based or inpatient education in terms of 3 different factors and overall. The survey was developed for this study. Patient satisfaction subscales were validated using Cronbach's alpha.

Surveys on diabetes knowledge, family impact, and quality of life were completed at 3 and again at 9 months post-diagnosis. The Diabetes Knowledge Questionnaire,[19] developed and validated for use in Australia in 2011, was completed by parents. Question 8, relating to foot problems, was removed as this was considered inappropriate for pediatric patients. The remaining 14 questions added to give a total possible score of 28. Family impact, or perceived burden of caring for a child with diabetes, was measured for children aged under 13 years at the time of diagnosis, using a version of the Problem Areas in Diabetes survey,[20] modified for completion by parents (PAID-PR).[21] This survey contains 18 statements describing possible diabetes-related problem areas which are scored according to level of agreement on a 5-point Likert scale, with higher scores indicating a higher impact. Participants aged over 10 at the time of diagnosis completed the modified Diabetes Quality of Life Instrument (DQOL),[22] adapted for use with children and adolescents from the original instrument developed for the Diabetes Control and Complications Trial.[23] This tool assesses quality of life in a range of areas and includes subscales for impact of diabetes (22 items) satisfaction with life (17 items) and diabetes-related worries (11 items). All items are scored using a 5-point Likert scale and for the impact and worries subscales, a higher

score indicates lower quality of life, and for the satisfaction subscale, the opposite applies. Overall health is self-rated as excellent, good, fair, or poor.

2.3 | Analyses

Statistics were analysed using IBM SPSS Statistics (Version 22). Proportions were compared using χ^2 or Fisher's exact tests. Confidence intervals for proportions were calculated using the asymptotic (Wald) method based on a normal approximation. Means were compared using student's t-tests. Demographic data are presented as mean $\pm$ standard deviation (SD) and other data as mean $\pm$ standard error of the mean (SE). $P < 0.05$ was considered significant.

3 | RESULTS

Of 190 patients presenting with newly diagnosed T1D during the recruitment period, 59 met the criteria for inclusion. Reasons for exclusion included living outside the HiTH catchment (N = 56), younger than 3 years (N = 18), assessed as socially unsuitable for early discharge (N = 16) or in DKA at presentation (N = 15). The remaining 26 patients were excluded for a range of reasons including not speaking English, unclear diagnosis or comorbid conditions. Of the eligible patients, 50 (85%) consented to the study with 25 randomized to each arm. One patient in the control group was excluded from the analysis due to a subsequent change of diagnosis from T1D to MODY (maturity onset diabetes of the young).

The 2 groups were similar in terms of measured baseline characteristics (Table 1).

Table 2 presents the clinical outcomes for the control and intervention groups at 12 months post-diagnosis. At the final clinic visit, there was no difference between the groups in mean HbA1c or any other measured medical outcomes. The average hospital length of stay (ALOS) at diagnosis was 1.9 days shorter for the home-based group than for the control group.

The outcomes of the surveys are presented in Table 3. Patient satisfaction surveys were completed for 100% participants at a mean $\pm$ SD of 29 $\pm$ 17 days post-diagnosis. Overall satisfaction was high in both groups, as was satisfaction for individual measures. The groups differed in their readiness for discharge, with 76% of the home-based group reporting they felt ready to be discharged after their 2-day inpatient stay, compared with 100% of the control group who felt ready at the end of their 5-day stay. Most respondents in

TABLE 1 Patient characteristics at baseline

	All (N = 49)	Home-based (N = 25)	Controls (N = 24)	P-value
Females, N (%)	30 (61)	17 (68)	13 (54)	0.32
Age at diagnosis, years (mean $\pm$ SD)	9.5 $\pm$ 3.1	10.1 $\pm$ 2.9	8.9 $\pm$ 3.2	0.16
HbA1c at diagnosis, % (mean $\pm$ SD)	12.3 $\pm$ 1.8	11.9 $\pm$ 1.9	12.7 $\pm$ 1.7	0.13
PAT[a] score (mean $\pm$ SD)	1.0 $\pm$ 0.7	1.1 $\pm$ 0.7	0.8 $\pm$ 0.6	0.10
SEIFA[b] quintile, N (%)				
1 (most disadvantaged)	4 (8)	2 (8)	2 (8)	
2	7 (14)	4 (16)	3 (12)	
3	6 (12)	2 (8)	4 (17)	
4	11 (22)	6 (24)	5 (21)	
5 (least disadvantaged)	21 (43)	11 (44)	10 (42)	

[a] PAT, psychosocial assessment tool,[31,32] administered by social worker within 2 weeks of diagnosis. Scoring range 0 (lowest risk) to 3 (highest risk).

[b] SEIFA, socio-economic index for area, based on postcode at diagnosis. χ^2 test not valid due to small numbers.

TABLE 2 Clinical outcomes at 12 months post-diagnosis[a]

	All (N = 49)	Home-based (N = 25)	Controls (N = 24)	P-value[b]
HbA1c, % (mean $\pm$ SE)	7.3 $\pm$ 0.2	7.4 $\pm$ 0.3	7.2 $\pm$ 0.2	0.66
Severe hypoglycemic events, N	0	0	0	
Diabetes-related hospital readmissions, N	0	0	0	
ALOS, days (mean $\pm$ SE)	3.6 $\pm$ 0.2	2.7 $\pm$ 0.2	4.6 $\pm$ 0.2	<0.01
Insulin TDD, units/kg (mean $\pm$ SE)	0.58 $\pm$ 0.04	0.57 $\pm$ 0.03	0.59 $\pm$ 0.06	0.88
Insulin regimen CSII, N	6	2	4	0.41[c]
Clinic visits per patient, N (mean $\pm$ SE)	6.2 $\pm$ 0.1	6.3 $\pm$ 0.2	6.2 $\pm$ 0.2	0.56

Abbreviations: ALOS, average hospital length of stay; CSII, continuous subcutaneous insulin infusion or pump therapy.

[a] HbA1c, TDD, and insulin regimen are as at the final clinic visit for the 12-month period. Hypoglycemic events and hospital readmissions are totalled for the period from diagnosis to final clinic visit.

[b] P-value is determined for home-based vs controls.

[c] Fisher's exact test.

TABLE 3 Survey scores, mean ± S.E[a]

Survey	Measure	Scoring range		All (N = 49)	Home-based (N = 25)	Controls (N = 24)	P-value[b]
Patient satisfaction	Overall	3-15		14.6 ± 0.1	14.5 ± 0.2	14.8 ± 0.1	0.31
	Admission	4-20		18.9 ± 0.2	18.8 ± 0.3	19.0 ± 0.3	0.54
	Staff	8-40		37.0 ± 0.5	37.1 ± 0.8	37.0 ± 0.6	0.94
	Support	5-25		23.4 ± 0.3	23.3 ± 0.5	23.5 ± 0.4	0.80
	Education	5-10		9.7 ± 0.1	9.7 ± 0.2	9.7 ± 0.1	0.97
	Discharge	2-10		8.6 ± 0.2	8.0 ± 0.4	9.2 ± 0.2	0.01
	Confidence	5-25		23.0 ± 0.3	23.2 ± 0.4	22.9 ± 0.4	0.59
Diabetes knowledge		0-28	3 m	22.0 ± 0.4	21.9 ± 0.6	22.2 ± 0.6	0.78
			9 m	22.6 ± 0.5	22.4 ± 0.7	22.9 ± 0.6	0.61
				3 m (N = 43) 9 m (N = 44)	(N = 21)	3 m (N = 22) 9 m (N = 23)	
PAID-PR		0-100	3 m	62.8 ± 2.9	64.1 ± 3.8	61.5 ± 4.4	0.67
			9 m	60.2 ± 2.8	59.8 ± 3.8	60.5 ± 4.2	0.91
				(N = 21)	(N = 12)	(N = 9)	
Quality of life	Impact	22-110	3 m	41.3 ± 2.9	38.7 ± 2.7	44.9 ± 5.8	0.31
			9 m	35.0 ± 2.4	32.0 ± 2.1	39.1 ± 4.6	0.14
	Satisfaction	17-85	3 m	65.7 ± 2.3	66.7 ± 2.5	64.4 ± 4.2	0.64
			9 m	68.9 ± 2.2	68.9 ± 2.7	69.0 ± 3.8	0.98
	Worries	11-55	3 m	22.2 ± 2.2	20.1 ± 2.3	25.0 ± 4.1	0.28
			9 m	19.0 ± 1.9	18.7 ± 2.6	19.4 ± 3.2	0.86
	Overall health rated > 2, N (%)	1-Poor 2-Fair 3-Good 4-Excellent	3 m 9 m	13 (61.9) 14 (66.7)	5 (41.7) 9 (75.0)	8 (88.9) 5 (55.6)	0.07 0.40

Abbreviation: PAID-PR, problem areas in diabetes—parent version.

[a] PAID-PR and quality of life surveys were restricted to participants aged <13 y (N = 44) and >10 y (N = 21) at the time of diagnosis, respectively.

[b] P-value is determined for home-based vs controls.

the home-based group reported feeling quite (52%) or very confident (40%) in managing diabetes in their first 2 weeks post-discharge and all but 1 respondent in this group found the HiTH visits to be quite (40%) or very (56%) helpful. Respondents for both groups combined indicated that with hindsight, most would choose home- over hospital-based education overall (69% vs 19%) and in terms of convenience (78% vs 16%) and impact on family (80% vs 14%). For access to help when required, the same number of respondents selected home- and hospital-based education (43% for both).

Knowledge, PAID-PR, and quality of life surveys were completed at a mean ± SD of 123 ± 45 and 299 ± 50 days post-diagnosis for the 3- and 9-month follow-ups, respectively. With the exception of 1 PAID-PR survey (3 m), completion was 100% for all surveys.

The study required additional staff time to coordinate and complete home visits and to allow for the flexibility required to accommodate family availability and unanticipated interruptions and changes to plans. A high level analysis compared the cost of additional staff with bed day cost savings for patients in the intervention group of the study. Up to AUD$40 000 per month was saved, depending on the rate of recruitment. Indirect costs such as work days lost were not accounted for.

4 | DISCUSSION

Early discharge and home-based management of children with newly diagnosed type 1 diabetes produced clinical outcomes in the first year comparable with those of children managed as inpatients. The time spent in hospital after diagnosis was reduced without impacting on measured psychosocial outcomes—perceived burden of caring for a child with diabetes and self-reported quality of life in patients aged over 10 years.

The equivalence in clinical outcomes at 12 months post-diagnosis is supportive of early discharge programs. Previous trials have similarly reported no disadvantages to home-based care but dedicated staffing and increased time spent educating patients and families in the home environment may have been a factor.[13,15] By contrast, in the current RCT, patients in both groups were educated by members of the same diabetes team using identical materials.

No patients in either group were readmitted or reported severe hypoglycemic events in the year after diagnosis. Previous retrospective studies have reported fewer readmissions for diabetes-related reasons in children managed at home,[7,24] citing possible reasons that include the encouragement of self-reliance knowing that professional help is readily available if needed. It has been suggested that home management downplays the seriousness of diabetes and may result

in poorer long-term outcomes,[25] however qualitative studies of parental experiences do not support this hypothesis.[26,27] In the current study there was no difference between the groups in glycemic control in the year following diagnosis, an important factor in predicting long-term control and associated risk of complications.[28]

There were no significant differences in perceived impact for parents and quality of life for children over 10 years and although the home-based group rated their overall health lower than the controls at 3 months, there was no difference between the groups by 9 months post-diagnosis. A recent UK study found that the setting for early treatment did not appear to have a differential impact on families in the long term[27] and other studies have reported no difference in a range of psychosocial measures including stress, coping, satisfaction, and quality of life.[8,13] Tiberg et al reported higher social functioning in a group discharged early for home-based education, possibly attributable to a difference in how parents view their situation over time and the extent to which they are able to integrate the child's care with a social life.[15] The earlier return to normal home life made possible by home-based or outpatient education and the possible reduction in perception that diabetes is an "illness" requiring hospitalization may be important factors in facilitating adjustment.

Parental diabetes knowledge was not impacted by delivery of detailed educational material in a home environment rather than a hospital. Other studies have also found diabetes knowledge to be unaffected by the setting in which it is delivered.[8,10,13] Advocates for admission at diagnosis argue that distress following diagnosis makes it difficult for parents to retain information and being asked to take charge of tasks immediately is very stressful.[29] The hybrid model trialed in this study allowed parents a 2 day "buffer" to adjust to the diagnosis while receiving 24-hour support in a hospital environment. Learning basic practical tasks prior to discharge was prioritized and more detailed theoretical education could then be delivered at a slower pace over an extended period following discharge.

Parents indicated that given the choice, most would have elected early discharge. Parents of patients discharged after 2 days felt less ready for discharge than those whose children had been in hospital for the duration of their initial education, but most parents in the home-based group felt confident to manage their child's diabetes after returning home and by 1 month post-diagnosis there was no difference in the confidence reported by each group. Qualitative assessments suggest that home-based care of children at diagnosis empowers parents, allowing them to integrate diabetes management into their everyday routines more quickly and reducing the initial impact of the disease.[26] Our results support this assertion, with families indicating that a short inpatient stay followed by home-based management is more convenient and causes less impact on the family. Access to help when required was not perceived to be a limiting factor of home-based management and the provision of 24 hour phone support is likely an important factor if patients are to be discharged early. The home visits by HiTH provided another point of contact for patients following discharge and were an important part of helping parents to gain confidence in managing their child's diabetes.

This study resulted in bed day savings of approximately 2 days per patient. In practice, the inpatient stay associated with an early discharge program would likely be lower than the 2.7 days observed

in this study as the time requirement for patients and families to consider the study information and provide consent would be removed. Clinical staff learned a great deal about the challenges faced by families following a T1D diagnosis by conducting home visits and seeing firsthand some of the issues encountered in adjusting to the demands of managing the disease. These lessons learned will help to inform future ambulatory models for children newly diagnosed with T1D. Feedback from health-care professionals involved in the home visits emphasised the value of "situational learning" for the family and the insight gained by staff into the family functioning.

Additional staff time was required to coordinate and complete home visits and to allow for the flexibility required to accommodate family availability and unanticipated interruptions and changes to plans. Adequate staffing for an ambulatory model was recognized as critical, due to the flexibility required to accommodate family availability and the importance of staff consistency and building a relationship of trust from the outset.

Each health service is different and the challenge of developing a sustainable ambulatory model must take account of a range of factors including the geographical area covered, patient numbers, availability and suitability of outpatient facilities, and availability and flexibility of multi-disciplinary team members. The potential saving in hospital bed days needs to be weighed against the additional staffing requirements and any other costs associated with an ambulatory model. Combining a single home visit with outpatient appointments for education may be a viable option that incorporates the advantages of home-based learning but reduces the staffing overheads.

The design was a major strength of this study, removing the differences between inpatient and outpatient comparator groups inherent in retrospective studies. A large proportion of patients were excluded from the study for a variety of reasons. It is feasible that rural patients could participate in an ambulatory program if alternative accommodation options were available and other groups may also be able to take part with appropriate support but the generalizability of our results is unknown. Additional limitations of the study include the psychosocial assessments which were applicable only to a subset of participants, reducing the number of responses. Surveys were also limited in scope and ideally more comprehensive psychosocial assessments would be completed, however, the burden on study participants is a consideration.

T1D is a life-long disease and effective education at disease onset is critical to self-management and optimal long-term outcomes.[30] Although numerous studies have previously reported on the feasibility, safety, and effectiveness of various ambulatory models for children newly diagnosed with T1D, there has been limited endorsement of ambulatory care in general because of the lack of high quality evidence available. As healthcare systems face ever-increasing demands there is growing pressure on healthcare providers to adopt ambulatory alternatives for new onset pediatric T1D and renewed interest in understanding the impact on health outcomes and costs. This study supports a hybrid model that incorporates a short inpatient stay at diagnosis for initial stabilization and teaching of basic practical skills. With appropriate staffing and support for patients and their families, early discharge could result in significant bed day savings without compromising patient care.

REFERENCES

1. Haynes A, Bower C, Bulsara MK, Jones TW, Davis EA. Continued increase in the incidence of childhood type 1 diabetes in a population-based Australian sample (1985–2002). *Diabetologia*. 2004;47(5):866-870.
2. Patterson CC, Dahlquist GG, Gyürüs E, Green A, Soltész G, EURO-DIAB Study Group. Incidence trends for childhood type 1 diabetes in Europe during 1989–2003 and predicted new cases 2005–20: a multicentre prospective registration study. *Lancet*. 2009;373:2027-2033.
3. Konrad, K, Vogel, C, Bollow, E, et al. Current practice of diabetes education in children and adolescents with type 1 diabetes in Germany and Austria: analysis based on the German/Austrian DPV database. *Pediatr Diabetes*. 2016;17:483-491.
4. Simell T, Simell O, Sintonen H. The first two years of type 1 diabetes in children: length of the initial hospital stay affects costs but not effectiveness of care. *Diabet Med*. 1993;10:855-862.
5. Wennick A, Hallström I. Swedish families' lived experience when a child is first diagnosed as having insulin-dependent diabetes mellitus: an ongoing learning experience. *J Fam Nurs*. 2006;12(4):368-389.
6. Koizumi S. Japanese mothers' responses to the diagnosis of childhood diabetes. *J Pediatr Nurs*. 1992;7:154-160.
7. Swift PGF, Hearnshaw JR, Botha JL, Wright G, Raymond NT, Jamieson KF. A decade of diabetes: keeping children out of hospital. *Br Med J*. 1993;307:96-98.
8. Siminerio LM, Charron-Prochownik D, Banion C, Schrelner B. Comparing outpatient and inpatient diabetes education for newly diagnosed pediatric patients. *Diabetes Educ*. 1999;25(6):895-906.
9. Tonyushkina KN, Visintainer PF, Jasinski CF, Wadzinski TL, Allen HF. Site of initial diabetes education does not affect metabolic outcomes in children with T1DM. *Pediatr Diabetes*. 2014;15:135-141.
10. Srinivasan S, Craig ME, Beeney L, et al. An ambulatory stabilisation program for children with newly diagnosed type 1 diabetes. *Med J Aust*. 2004;180:277-280.
11. Clar C, Waugh N, Thomas S. Routine hospital admission versus outpatient or home care in children at diagnosis of type 1 diabetes mellitus. *Cochrane Database Syst Rev*. 2007;2:CD004099.
12. Lowes L, Gregory JW. Management of newly diagnosed diabetes: home or hospital? *Arch Dis Child*. 2004;89(10):934-937.
13. Dougherty G, Schiffrin A, White D, Soderstrom L, Sufrategui M. Home-based management can achieve intensification cost-effectively in type I diabetes. *Pediatrics*. 1999;103(1):122-128.
14. Jasinski CF, Rodriguez-Monguio R, Tonyushkina K, Allen H. Health-care cost of type 1 diabetes mellitus in new-onset children in a hospital compared to an outpatient setting. *BMC Pediatr*. 2013;13:55.
15. Tiberg I, Hallström I, Jönsson L, Carlsson A. Comparison of hospital-based and hospital-based home care at diabetes onset in children. *Eur Diabetes Nursing*. 2014;11(3):70-74.
16. Chase HP, Crews KR, Garg S, et al. Outpatient management vs in-hospital management of children with new-onset diabetes. *Clin Pediatr (Phila)*. 1992;31(8):450-456.
17. AIHW. *Incidence of Type 1 Diabetes in Australian Children 2000–2008*, 2010 Diabetes Series No 13 Canberra, Australia: Australian Government Publishing Service.
18. Townson JK, Gregory JW, Cohen D, et al. Delivering early care in diabetes evaluation (DECIDE): a protocol for a randomised controlled trial to assess hospital versus home management at diagnosis in childhood diabetes. *BMC Pediatr*. 2011;11(1):7.
19. Eigenmann CA, Skinner T, Colagiuri R. Development and validation of a diabetes knowledge questionnaire. *Practical Diabetes International*. 2011;28(4):166-70d.
20. Polonsky WH, Anderson BJ, Lohrer PA, et al. Assessment of diabetes-related distress. *Diabetes Care*. 1995;18(6):754-760.
21. Markowitz JT, Volkening LK, Butler DA, Antisdel-Lomaglio J, Anderson BJ, Laffel LMB. Re-examining a measure of diabetes-related burden in parents of young people with Type 1 diabetes: the Problem Areas in Diabetes Survey – Parent Revised version (PAID-PR). *Diabet Med*. 2012;29(4):526-530.
22. Ingersoll GM, Marrero DG. A modified quality-of-life measure for youths: psychometric properties. *Diabetes Educ*. 1991;17:114-118.
23. The DCCT Research Group. Reliability and validity of a diabetes quality-of-life measure for the diabetes control and complications trial (DCCT). *Diabetes Care*. 1988;11(9):725-732.
24. Lee PDK. An outpatient-focused program for childhood diabetes: design, implementation and effectiveness. *Tex Med*. 1992;88(7):64-68.
25. Scott A, Donnelly R. Improving outcomes for young people with diabetes: use of new technology and a skills-based training approach is urgently needed. *Diabet Med*. 2001;18(11):861-863.
26. Lowes L, Lyne P, Gregory JW. Childhood diabetes: parents' experience of home management and the first year following diagnosis. *Diabet Med*. 2004;21(6):531-538.
27. Morgan-Trimmer S, Channon S, Gregory JW, Townson J, Lowes L. Family preferences for home or hospital care at diagnosis for children with diabetes in the DECIDE study. *Diabet Med*. 2016;33(1):119-124.
28. Samuelsson U, Steineck I, Gubbjornsdottir S. A high mean-HbA1c value 3–15 months after diagnosis of type 1 diabetes in childhood is related to metabolic control, macroalbuminuria, and retinopathy in early adulthood - a pilot study using two nation-wide population based quality registries. *Pediatr Diabetes*. 2014;15(3):229-235.
29. Grey M, Doyle EA. Should children with type 1 diabetes be hospitalized at diagnosis? *MCN Am J Matern Child Nurs*. 2011;36(4):214-215.
30. Funnell MM, Brown TL, Childs BP, et al. National standards for diabetes self-management education. *Diabetes Care*. 2009;32(Suppl. 1):S87-S94.
31. Kazak AE, Prusak A, McSherry M, et al. The psychosocial assessment tool (PAT): pilot data on a brief screening instrument for identifying high risk families in pediatric oncology. *Fam Syst Health*. 2001;19(3):303-317.
32. Pai ALH, Patiño-Fernández AM, McSherry M, et al. The psychosocial assessment tool (PAT2.0): psychometric properties of a screener for psychosocial distress in families of children newly diagnosed with cancer. *J Pediatr Psychol*. 2008;33(1):50-62.

How to cite this article: Clapin H, Hop L, Ritchie E, et al. Home-based vs inpatient education for children newly diagnosed with type 1 diabetes. *Pediatric Diabetes*. 2017;18:579–587. https://doi.org/10.1111/pedi.12466

APPENDIX

Patient satisfaction survey

Name:				Date:				
CONSIDERING THE PERIOD SINCE YOUR CHILD'S DIAGNOSIS …..								
PLEASE ANSWER ALL QUESTIONS 1 TO 23:				(circle the most appropriate response)				

OVERALL		Very poor	Poor	Just ok	Good	Very good
1	Overall, how would you rate the medical care you have received?	1	2	3	4	5
2	Overall, how would you rate the education you have received?	1	2	3	4	5
3	Overall, how would you rate the support you have received?	1	2	3	4	5

ADMISSION		Very poor	Poor	Just ok	Good	Very good
4	The care you received in Emergency was…………………	1	2	3	4	5
5	The way in which the diagnosis of diabetes was communicated to you was………………………….……	1	2	3	4	5
6	The way the process of care was explained to you was……	1	2	3	4	5
7	The explanation of the Diabetes team member roles was…	1	2	3	4	5

STAFF AVAILABILITY		Very poor	Poor	Just ok	Good	Very good
8	Availability of Diabetes team to speak with you during your hospital stay:					
	Doctor availability during hospital stay was……………	1	2	3	4	5
	Nurse Educator availability during hospital stay was…..	1	2	3	4	5
	Dietitian availability during hospital stay was………...	1	2	3	4	5
	Social worker availability during hospital stay was….....	1	2	3	4	5
9	Availability of Diabetes team to speak with you after discharge:					
	Doctor availability after discharge was……………….	1	2	3	4	5
	Nurse Educator availability after discharge was………	1	2	3	4	5
	Dietitian availability after discharge was…………....	1	2	3	4	5
	Social worker availability after discharge was…...........	1	2	3	4	5

SUPPORT		Very poor	Poor	Just ok	Good	Very good
10	The support received regarding adjusting and coping with diabetes diagnosis:					
	Doctor support was…..…………………………..	1	2	3	4	5
	Nurse Educator support was ………………………	1	2	3	4	5
	Dietitian support was ………………………………	1	2	3	4	5
	Social worker support was…………………………	1	2	3	4	5

11	Support and assistance from ward nursing staff when you first started giving your child insulin in hospital was……	1	2	3	4	5

EDUCATION SESSIONS

12	Was the length of the education sessions ok? If no, provide details:	Yes	No
13	Was the number of education sessions ok? If no, provide details:	Yes	No
14	Were the education times convenient? If no, provide details:	Yes	No
15	Was the information provided in the education sessions clear? If no, provide details:	Yes	No
16	Was the information provided by the social worker useful? If no, provide details:	Yes	No

DISCHARGE FROM PMH		Not at all ready	Not quite ready	Just ok	Ready	Very ready
17	How ready did you feel to be discharged from PMH?	1	2	3	4	5
18	How ready did you feel your child was to be discharged from PMH?	1	2	3	4	5

HOW CONFIDENT DO YOU FEEL NOW ……..		Not at all	Not very	Just ok	Quite	Very
19	To manage your child's insulin administration at home?	1	2	3	4	5
20	To manage your child's diet at home?	1	2	3	4	5
21	To manage your child's blood glucose testing at home?	1	2	3	4	5
22	To manage a hypoglycemic episode at home?	1	2	3	4	5
23	In receiving support from the diabetes team for assistance in any aspects of managing diabetes at home?	1	2	3	4	5

IF YOU WERE DISCHARGED EARLY AND VISITED BY THE DIABETES TEAM AT HOME THEN GO TO QUESTION 25

In-patient education group

24   Imagine what it would have been like to be discharged within the first two days after diagnosis. Phone support would have been available at all times and nursing staff would have visited you to assist with insulin administration for the first 48 hours. A diabetes education team would have visited at agreed times on three separate occasions in the two weeks following discharge to complete your education sessions at home.

How do you think that this would compare with your experience of remaining in hospital for the same education? Which do you think that you would you prefer in terms of the following:

Convenience……………………….……………………..	Hospital	Home	No preference
Impact on your family ……………………………..	Hospital	Home	No preference
Your access to help when required ……………………	Hospital	Home	No preference

GO TO QUESTION 28

Home-based education group

25	Did you feel confident in managing your child's diabetes throughout the first two week period while you were receiving education at home?	Not at all	Not very	Just ok	Quite	Very
26	Would you say that the nursing staff who visited you at home in the first 48 hours after discharge were helpful in terms of your confidence in managing your child's diabetes?	Not at all	Not very	Just ok	Quite	Very

27 Imagine what it would have been like to remain in hospital for 5-6 days to complete your diabetes education.

How do you think that this would compare with your experience of being discharged early and being educated at home? Which do you think that you would you prefer in terms of the following:

Convenience………………………….…………………..	Hospital	Home	No preference
Impact on your family ……………………………..	Hospital	Home	No preference
Your access to help when required ……………………	Hospital	Home	No preference

Both groups

28 If you had the choice, would you prefer (circle one option):

A. To be discharged after basic practical education and receive more detailed education and theory at home (with full medical and nursing support) over a longer period of time, or

B. To remain in hospital for 5-6 days while receiving the same education, or

C. No preference