Home care for children and adolescents with type 1 diabetes: Is it feasible?

Jeremy Kirk, Emma Thomas

At presentation of type 1 diabetes most paediatric patients are well and could be home-managed if appropriate facilities were available. Initial diabetes home care from diagnosis appears to be equivalent to hospital-based care in terms of metabolic control, acute diabetic complications and readmission rates. Our own two-decade experience of diabetes home care at Birmingham Children's Hospital confirms its benefit – including a reduction in readmission rates for new and existing patients. Costs of the service are far outweighed by its savings (direct and indirect). One of a variety of models of home care may be applicable to many paediatric diabetes units.

Article points

1. Home care at diagnosis has been recommended, where possible, for newly diagnosed children and adolescents with type 1 diabetes.
2. The evidence indicates that home care at diagnosis is as equally effective as hospital-based care.
3. The benefits of diabetes home care – reduced bed-days for new and existing patients, improved metabolic control and cost-effectiveness – have been demonstrated in our unit over 20 years.
4. Although total home management may be unfeasible, some form of home care is applicable to many units.

Key words

- Type 1 diabetes
- Paediatric
- Adolescent
- Home care
- Ambulatory care

Jeremy Kirk is Consultant Paediatric Endocrinologist/ Diabetologist and Emma Thomas is Diabetes Home Care Coordinator, Birmingham Children's Hospital.

Type 1 diabetes is one of the most common chronic illnesses of childhood, with an increasing frequency in the UK (Gardner et al, 1997). The diagnosis of diabetes has profound implications for the individual and his/her family and its impact is considered by some as a 'psychological crisis' (Galatzer et al, 1982). Only a minority of children with newly diagnosed diabetes are unwell at diagnosis and consequently require hospital admission for medical reasons (Smith et al, 1998); potentially the child could, if well, commence therapy in the home environment. Disruption to the child and family could, therefore, be kept to a minimum.

Outpatient management of type 1 diabetes has been advocated for over 50 years (Walker, 1953), yet most children in the UK and abroad are still admitted to hospital for stabilisation at diagnosis, regardless of their clinical condition (Clar et al, 2003). Recently, the shift in emphasis away from hospital to home management of children with chronic and non-urgent conditions has recognised the need for hospital-based, community orientated paediatric services (Meates, 1997).

In the light of this evidence the recent National Institute for Health and Clinical Excellence (NICE) clinical guidelines on management of children and adolescents with type 1 diabetes (NICE, 2004) has recommended that:

> *'At the time of diagnosis, children and young people with type 1 diabetes should be offered home-based or inpatient management according to clinical need, family circumstances and wishes, and residential proximity to inpatient services.'*

It also goes on to state that:

> *'Home-based care with support from the local paediatric diabetes care team (including 24-*

hour telephone access to advice) is safe and as effective as inpatient initial management' (NICE, 2004).

Is this true? A Cochrane database review by Clar and colleagues (2003) attempted to systematically review the evidence for routine hospital admission compared with outpatient or home-based management in children newly diagnosed with type 1 diabetes who are not acutely ill. They assessed the type of care on metabolic control, well-being and self-efficacy of the patient and their family. The review itself was inconclusive due to the generally low quality and limited applicability of the studies, many of which had been performed retrospectively. Despite this, it indicated that outpatient/home management of type 1 diabetes in children at diagnosis did not lead, at follow-up, to a worsening of metabolic control (and in the best study, to an improvement), acute diabetes complications, hospital admissions, psychosocial variables and behaviour. However, total financial costs were the same, being improved for parents but counterbalanced by increased health costs.

Paediatric diabetes home care in the UK and Birmingham

Although the Audit Commission (2000) indicated a general reduction in the length of hospital admission at diagnosis of diabetes, apart from publications from a small number of units (Swift et al, 1993; Lowes and Gregory, 2004) there are limited data on home care at diagnosis in the UK. At Birmingham Children's Hospital, in response to a perceived need, a paediatric diabetes home care (DHC) unit was established in 1981. The initial benefits of the service were published in 1984 (Rayner, 1984), and the 20 year results in 2005 (McEvilly and Kirk, 2005). During this time the unit has grown from 230 children with diabetes based on a single site to 400 children spread over two (350 at the Children's Hospital and a further 50 at City Hospital). In order to cope with this increase, the numbers of paediatric diabetes specialist nurses (PDSNs) has increased from 2.0 to 3.6 whole-time-equivalent (WTE; currently there is a ratio of one WTE nurse to 111 patients), along with increases in medical, dietetic and administrative staff. As with many other UK units the recommended ratio of one WTE nurse per 100 patients is not achieved, and psychological support is very limited (Edge et al, 2005). The workload and activity of the unit has also risen during this time, and it has now also been successfully extended to another unit in Birmingham – City Hospital (Kirk et al, 2003).

The DHC service is available 24 hours a day. PDSNs are the first line of contact and work a shift system four days a week (0730–1730 and 1015–2000). PDSNs also provide routine and emergency visiting and on-call at the weekend. The consultant staff are on-call one in three for endocrinology and diabetes and also cover the PDSNs at times of holiday, illness or study leave.

Newly diagnosed patients

The DHC team initially review and assess all children with a diagnosis of diabetes. If the child is well, whenever possible they are sent home, usually following support for the first injection and initial education within the DHC. This enables the PDSN to meet the family and begin to establish a relationship. This meeting within the hospital also allows the PDSN to make risk assessment regarding the suitability of home management. This is followed by visits at home to continue education and support injections and other practical aspects of care in familiar surroundings.

Since mid-2005 adolescents aged 11 years and above have commenced multiple daily injections (MDI) at diagnosis. These young people receive the same 'package of care' as patients younger than 11 years apart from the first lunchtime bolus insulin, when they attend the DHC and take the opportunity to see the dietitian at that time. Remaining visits are carried out in the young person's home.

Home support for newly diagnosed individuals is provided initially at injection times for the first 2–3 days, and is then followed by visits at non-injection times

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1. Home support for newly diagnosed individuals is provided initially at injection times for the first 2–3 days, and is then followed by visits at non-injection times.
2. Admission to hospital at presentation is required for children who are unwell (for example diabetic ketoacidosis [DKA] or significant dehydration).
3. In addition to regular age-banded outpatient clinic visits, existing patients receive twice-yearly home visits (usually by the PDSN and dietitian).
4. There is, in addition, an informal nurse-led drop-in clinic in the hospital on Saturday mornings that is mainly accessed by adolescents.
5. Initial analysis of the service (Rayner, 1984) showed a fall in total inpatient bed-days.

(often in association with the dietitian) to continue education at a less stressful time. A patient-held record system is used, which includes contact details of the DHC nurses. Contact from families is actively encouraged, and guidance about when to get advice is also given. Six weeks following diagnosis the family's knowledge is formally assessed using a validated multiple choice questionnaire, and education reviewed as necessary. A similar questionnaire is repeated 12 months after diagnosis.

Admission to hospital at presentation is required for children who are unwell (for example diabetic ketoacidosis [DKA] or significant dehydration). Other reasons include adverse social circumstances, language difficulties, and logistic problems such as staff shortages (such as illness, study leave and annual leave) or several new patients presenting simultaneously. Even for these people hospital admission is usually brief (24–48 hours), with early contact on the ward from the PDSN and discharge home under their care for further management and education.

Existing patients

In addition to regular age-banded outpatient clinic visits, existing patients receive twice-yearly home visits (usually by the PDSN and dietitian), plus regular telephone contacts. The overall yearly number of telephone contacts remains high at >7000 (although the number of contacts varies enormously between individuals) and is an integral part of the support service.

There is, in addition, an informal nurse-led drop-in clinic in the hospital on Saturday mornings that is mainly accessed by adolescents. In this group, following planning for transfer, nursing and medical support is also provided in the young adult clinics as they move to adult care.

Adjustment of insulin, intercurrent illness and hypoglycaemia is managed whenever possible by the PDSNs working within agreed protocols. For those with poor glycaemic control, the nurses follow additional guidelines for support. In addition, national training of nursing and dietetic staff is provided via the onsite Management of Childhood Diabetes course, which has now been running for the last 15 years and is accredited at levels 5 and 6 (diploma and degree level). In 2002 an advanced course was also established at the University of Birmingham for the training of specialist registrars and newly appointed consultants.

Results

Figure 1 summarises data, for the period 1991–2003, on patients newly diagnosed with type 1 diabetes, the number of newly diagnosed patients who are totally managed at home and the total number of bed-days for newly diagnosed patients.

Bed-days

Initial analysis of the service (Rayner, 1984) showed a fall in total inpatient bed-days from 555 (prior to commencement of DHC) to 127 per year. There was also a decrease in the length of stay for newly diagnosed children (mean of 12.2 days in 1980 to 4.1 days in 1984). This had fallen further by 1994, when the average inpatient stay at diagnosis was 0.6 bed-days, with 66.6% totally home-managed (compared with 33.3% in 1989) and this reduction was sustained over subsequent years; in 2002 there were 28 bed-days for 35 newly diagnosed patients (0.8 bed-days per patient).

Was this reduction in inpatient time bought at the expense of increased nursing input? The answer is no; children admitted to hospital for stabilisation received an average of 11.6 hours of intensive nursing contact in the first two weeks following diagnosis, compared with 12.1 hours (excluding travel time) for those supported totally at home (1994 figures).

Readmission rates for existing patients also fell from an initial mean of 7.2 bed-days/patient/year in 1980 to 2.3 bed-days in 1983. By 1994 the readmission rate had fallen to 0.2 bed-days/patient/year, and has remained at this level since then. Many of these readmissions are due to DKA and the

median number of bed-days for all patients over the last 3 years has been 14/year (range 10–24), a readmission rate of 4.1 bed-days per 100 patients (range 2.9–7.1), which compares very well with other units. Much of this represents a small number of non-concordant individuals who are not in regular contact with the DHC.

Diabetes control

After inception of home care there was a fall in mean HbA_1 from 12.8% in 1981 to 11.6% in 1984, and this has remained lower, at 10.4% in 1987 and 10.5% in 1993. From 1994 we have measured HbA_{1c} (from 1997 using the DCA-2000 meter [Bayer Laboratories, Elkhart, USA]; results from 2000 onwards show a mean HbA_{1c} of 9.0–9.3%; which compares well with units nationally (Diabetes UK, 2003) and internationally (Danne et al, 2001).

Cost effectiveness

The original paper (Rayner, 1984) described a potential total saving of £26 415, based on the estimated saving of inpatient expenditure (£52 917), less the cost of the service itself (£26 502). An intermediate analysis in 1995, following the absorption of 40 patients from another unit (Selly Oak Hospital, Birmingham), estimated savings of £1129.50/patient/year, which were recalculated using figures from 2002. Even allowing for the trend towards reduction in hospital stay of newly diagnosed adolescents, the most recent data from the Audit Commission (2000) showed a mean stay of 3.0 bed-days/patient (based on 7 units), compared with 0.8 for the DHC unit. Readmission rates were 0.2 bed-days/patient/year (compared with 2.0 for non-home-care managed individuals). The savings were therefore 2.2 bed-days for 35 newly diagnosed individuals (77 bed-days) and 1.8 bed-days for 350 existing patients (630 bed-days); a total of 707 bed-days. At a current cost of £500 per diabetes-related bed-day this represented a potential saving of approximately £353 500, which outweighs the total cost of running the

Page points

1. After inception of home care there was a fall in mean HbA_1.
2. Considerable cost savings have also been demonstrated.

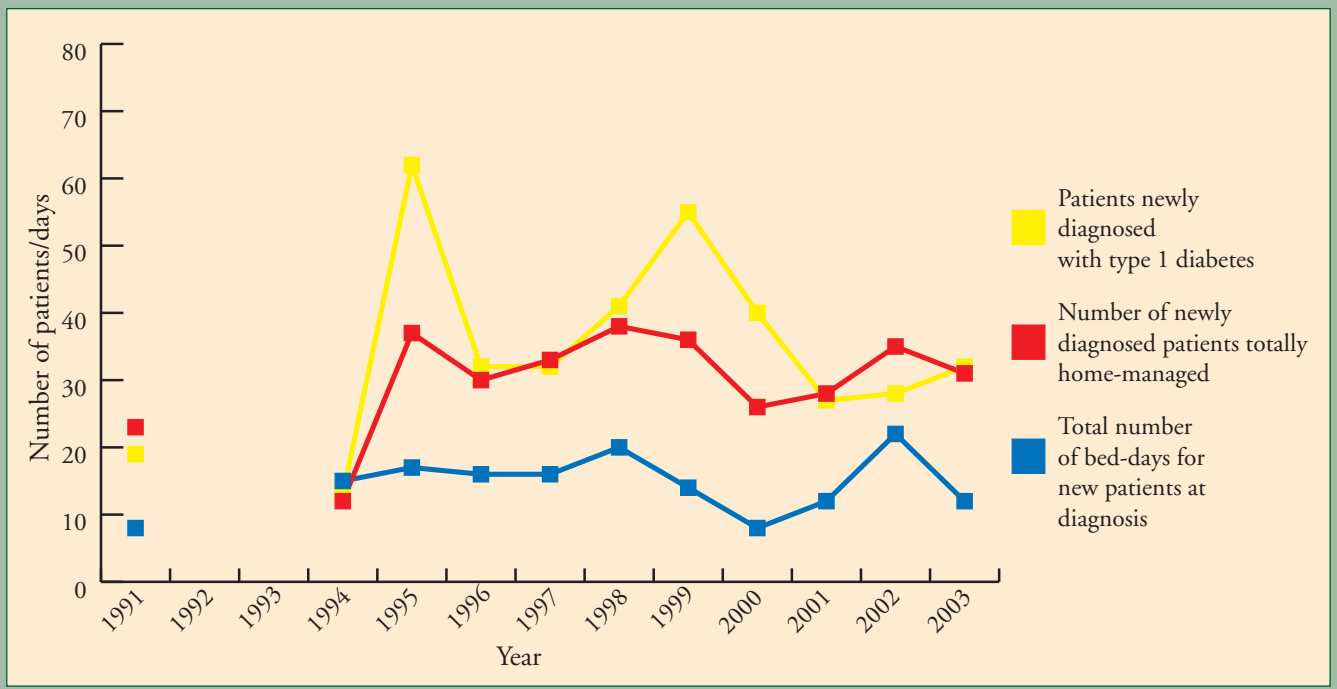

Figure 1. Number of patients (including number totally home-managed) and bed-days at diagnosis of type 1 diabetes at Birmingham Children's Hospital.

Page points

1. The evidence from the Cochrane review suggests that home care at diagnosis does not appear to be worse than existing models of inpatient care (Clar et al, 2003).
2. Some of the problem in analysing the data was the considerable variation in what is interpreted as 'home management', from no hospital admission up to 27 hours in hospital.
3. There is some evidence that home management can reduce readmissions, which will also have a short term economic benefit by a reduction in bed-day costs, as well as the economic savings arising due to improved metabolic control.
4. Although total home management is viewed as the 'gold standard', there is actually little evidence to support this in comparison to the other options, and some would argue that total home care sends out the wrong signals to children and their families about the severity of the condition.

unit.

Discussion

In addition to the NICE type 1 guidelines, the concept of home care for young people with diabetes has been recommended by a number of national and international groups (Audit Commission, 2000; International Society for Pediatric and Adolescent Diabetes, 2000; Department of Health, 2001, 2004). The evidence from the Cochrane review suggests that home care at diagnosis does not appear to be worse than existing models of inpatient care (Clar et al, 2003). It has been pointed out, however, that some of the problem in analysing the data was the considerable variation in what is interpreted as 'home management', from no hospital admission up to 27 hours in hospital (Lowes and Gregory, 2004). Despite this, there have also been a number of studies, mainly from North America, which do suggest a cost benefit of initial home management, or at least no difference between home and hospital management (Dougherty et al, 1998). There is, however, some evidence that home management can reduce readmissions (Swift et al, 1993), which will also have a short term economic benefit by a reduction in bed-day costs, as well as the economic savings arising due to improved metabolic control (Diabetes Control and Complications Trial Research Group, 1993).

At the authors' DHC unit the benefit of total home care for both new and existing patients has been shown, and, although labour intensive, is also cost-effective. It may not be feasible, however, for other, often smaller and more diffuse, units to provide the same level of home care. Lowes and Gregory (2004) stated that there are potentially four different approaches to initially managing children at diagnosis of diabetes:

- total home management
- ambulatory care (home from diagnosis but with injections and education performed in hospital)
- short hospital admission (<4 days)
- long hospital admission (>4 days).

There is already published evidence of the benefit of short-term versus long-term admissions (Simell et al, 2001), and most units now have shorter admissions periods than previously (Audit Commission, 2000). Other units abroad, such as Vancouver, have published experience of ambulatory care (Vancouver/Richmond Health Board, 1997).

Although total home management is viewed as the 'gold standard', there is actually little evidence to support this in comparison to the other options, and some would argue that total home care sends out the wrong signals to children and their families about the severity of the condition (Scott and Donelly, 2001). There are also significant logistical problems even in the largest units of maintaining total home care, with increasing numbers of patients and the trend towards multiple daily injections, in the face of overstretched nursing teams. Even in a unit of our size, with relatively good staffing levels – better than the national average of one WTE PDSN to 147 patients (Edge et al, 2005), and a relatively small defined geographical area (approximating to a radius of 10 miles around the Children's Hospital), over the last few years we have struggled to provide total home care, especially during staff holidays and illness. Although we have demonstrated significant (potential) savings short-term by freeing up inpatient bed-days and long-term by improving metabolic control the upcoming payment by results may well impact on them.

Conclusions

Data from the literature indicate that most children at presentation with diabetes could be home-managed. The evidence to date does not appear to show any worse (and possibly better) outcomes in those patients who are home-managed, and this is confirmed by our experience over 20 years at Birmingham Children's Hospital both

for new and existing patients. Although total home care is considered to be the 'gold standard' there is little evidence to support it, and various forms of ambulatory care may be more appropriate for many units. ■

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