Insulin pump initiation and education for children and adolescents – a qualitative study of current practice in New Zealand

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Received: 25 June 2018 / Accepted: 4 February 2019 / Published online: 12 February 2019
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Abstract

Purpose Worldwide, the use of insulin pumps for the management of type 1 diabetes is increasing. There are no national or international published guidelines and few guidance recommendations detailing the education and training required to commence insulin pump therapy. The aim of this study is to describe current clinical practice regarding initiation of insulin pump therapy in children and adolescents with type 1 diabetes in New Zealand.

Methods Pediatric diabetes nurse specialists from selected New Zealand hospitals ($n = 16$) were identified and invited to participate in this qualitative study. For those consenting, structured interviews were conducted. The questions covered basic hospital demographics and various aspects of insulin pump initiation including pump start planning, education, and aspects of follow-up and after-care.

Results The response rate was 100% (16 out of 16 hospitals). Diabetes clinics interviewed varied in size from 50 to 450 pediatric patients and frequency of insulin pump use from 11% - 46%. Clinical practice differed between clinics. Important differences related to: use of continuous glucose monitoring (12/16); and differing views on immediate vs. delayed use of pump advanced features. Location of pump starts also varied, with both in-patient (2/16) and out-patient (14/16) approaches seen. The motivations and beliefs relating to these various pump start approaches also varied.

Conclusions Differences seen between hospitals reflected team preference, and possibly a lack of consensus/guidance from the medical literature. Lessons may be learnt and further rationalisation and improvement in education remains possible by combining and adopting strengths from different hospitals.

Keywords Type 1 diabetes · Pediatric · Education · Insulin pump · Continuous subcutaneous insulin infusion

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Following the findings of landmark studies such as the Diabetes Control and Complications Trial (DCCT) [1] the use of intensive insulin therapy has increased [2, 3]. Insulin pumps offer a number of potential advantages over multiple daily injections, including improved flexibility, improved quality of life, decrease in severe hypoglycaemic events and improvements in glycated haemoglobin levels (HbA1c) [4–7]. However, insulin pump use also has disadvantages, with research now highlighting potential adverse events, such as pump or infusion-set failure, as well as cutaneous complications [8, 9]. Key conclusions from these papers on pump adverse events are that education and anticipatory guidance are important factors in improving the user experience and preventing serious potential complications [8, 10].

Quality education and support to the patient and family have always been key aspects of type 1 diabetes mellitus (T1DM) management, and are likely to be as important for

long-term diabetes success as intensive therapy and technology [3, 11]. For insulin pump therapy this is arguably even more important, as this technology often requires more initial training and ongoing support than traditional injection approaches [3, 12].

Despite the obvious requirements for and benefits of appropriate training and support for insulin pump therapy, there are currently relatively few guidance recommendations and no published guidelines relating to insulin pump initiation, education, and training [13]. In addition, there are no published data describing exactly how pump education actually occurs in the real world.

In response to this, the aim of the study was to describe current clinical practice regarding initiation of insulin pump therapy in children and adolescents with type 1 diabetes in New Zealand.

Methods

Study design

A descriptive qualitative study design comprising structured interviews with pediatric diabetes nurse specialists (DNS) was used to explore how pediatric diabetes teams in New Zealand conduct insulin pump training. The structured interview schedule was determined from focus group discussions and interviews with various health professionals, including: pediatric endocrinologists, DNSs, an academic pharmacist, pediatric dieticians and an insulin pump company educator. This process also identified the DNS as the staff member most likely to be intimately involved in all practical aspects of insulin pump training.

The survey questions covered three themes as follows:

1. Pre-pump start preparation and planning, covering demographic aspects of the hospital, aspects of preparation for initiating pump therapy including: selection criteria, pump and infusion set choices, carbohydrate counting preparation, and funding.
2. Training and education days, including questions relating to activities and education carried out during pump initiation.
3. Post education monitoring and follow up, including questions pertaining to monitoring of the patient in the initial period post commencement (including the use of the Continuous glucose monitoring System (CGMS)), and ongoing education and emergency contacts.

Study setting and participants

The study was conducted from February 2016 to April 2016. Selection of study sites involved consultation with the

Pediatric Society of New Zealand Diabetes Clinical Network – the main professional organisation in the New Zealand involved in pediatric diabetes care. The key inclusion criterion was determined by diabetes service size, with all New Zealand diabetes teams with >20 pediatric diabetes patients selected. This resulted in 16 New Zealand hospitals being identified. A lead pediatrician or pediatric endocrinologist was then contacted from each hospital and asked to nominate a DNS closely involved with training and education of pediatric and adolescent patients commencing insulin pump therapy. Once identified, the DNS was invited to participate via email/phone. In two instances the original DNS identified was not available, and an alternative DNS was identified and approached.

Data collection and analysis

Interviews were conducted by the first author. All interviews were digitally recorded and transcribed. For analysis and presentation, interview results were ordered into three sections corresponding to the three themes of the structured interview. These individual responses were then examined and compared, with responses presented as descriptive data, and descriptive comparisons made of current practice within New Zealand.

Ethical approval for this project was granted through the University of Otago, New Zealand, Human Ethics Committee (reference number D16/057), in accordance with the Declaration of Helsinki.

Results

In total, a DNS from 16 out of 16 (100%) public hospitals approached agreed to participate. Interviews lasted a median time of 48 min (range 25–70 min).

Pre-pump start preparation and planning

In 9/16 New Zealand hospitals there was a strong drive to commence younger patients on insulin pumps – but no specific restrictions for access, other than, the requirement to fulfil government criteria for public funding [14]. The criteria used to prioritise patients were largely similar between centres in New Zealand. Such factors included the patient's age, variation in blood glucose level, frequency of hypoglycaemia and an understanding of the amount of monitoring and dose adjusting that needs to be done when on insulin pump therapy.

A common factor reported was the belief that the individual patient must want the pump, with the view that this had a strong influence on the subsequent success.

The following quotes highlight these findings:

“The child also wanting to be on the pump, we take that very seriously as well because we think if the child doesn’t tolerate the pump, then it is probably not going to be something that is going to work well anyway” - DNS Centre G

“It doesn’t just need to be based on HbA1C but also based on quality of life that is just as valid as whether it is going to improve their HbA1C” – DNS Centre N

As seen in Table 1, a preference for Animas™ brand pumps was found. Multiple participants stated that the factors which influenced their centre pump preference were team experience, the company having a well-structured pump training program, excellent provision of resources, and high quality 24-h patient support highlighted by multiple responders. Some hospitals stated that brand recommendations would differ based on patient characteristics e.g. a larger/older patient might be recommended a Medtronic™ pump due to the larger insulin reservoir (3 ml vs 2 ml in Animas™).

Training and education days

A range of pump start activities and education strategies were identified for the initiation of pump use. The range in total duration was a notable issue, as well as the extent of in- vs out-patient education. The majority of hospitals’ formal pump training sessions spanned two working days (total duration of contact time 6–21 h, median 13.5 h), and in 14/16 (88%) all training was conducted as out-patient day cases.

The method of transition from multiple daily injection (MDI) insulin to the insulin pump also varied, and depended on when the long acting insulin was given, 10/16 hospitals would recommend stopping the long acting dose the night before. 3/16 hospitals still gave the long acting dose the night before pump start, with 2 of these recommending a 20–50% reduction in the dose. Another 3/16 New Zealand hospitals recommended a 24 h washout of the long acting insulin prior

to the pump start session, utilising rapid acting insulin only on an as needed basis (Table 2).

The introduction of the use of pump “smart features” also demonstrated polarised views with both immediate and delayed use seen with 50% of teams starting these immediately (often giving safety and simplicity as reasons). In contrast the remaining 50% delayed use, again also quoting safety as a reason, and the perception that it was important for patients and their families to be able to calculate and demonstrate proficiency in manual insulin calculations before using automation. The following quote represents this perception:

“We find that as soon as you turn on the smart features people become very reliant on them and it’s about that logic and can they actually manually work things out if they need to because we think that is actually really important” - DNS Centre A

Post education monitoring and follow up

As shown in Tables 3, 12/16 centres interviewed provided CGMS for up to two weeks post initiation of pump therapy. The CGMS device was usually funded by the individual DHBs rather than the individual with diabetes, or the insulin pump company.

CGMS, Continuous Glucose Monitoring System.

It was found that how often CGMS and blood glucose records (for the purposes of insulin adjustment and safety) were reviewed varied between hospitals, with once daily review of records dominant (12/16), then twice daily (1/16), twice weekly (1/16), every 2 days (1/16) or once weekly (1/16).

All hospitals interviewed stated that the patient was referred to the company representative/phone support for any technical issues relating to the pump. In terms of clinical issues there was variability in the extent of support provided to patients. Regarding support after hours during out-patient pump starts, 8/16 hospitals had a DNS officially “on-call” for the patient’s clinical queries and 1/16 hospital had a DNS

Table 1 Pre-pump start preparation and planning

	Participants (n = 16)
Clinic diabetes population, median (range)	70 (50–450)
Pump patients (%), median (range)	26% (10–46%)
Patient age range (years)	0–18
Pump initiation selection criteria	PHARMAC ^a (+ Clinical)
Dominant pump (estimated values)	Animas™ (~ 90%)
Infusion set preference	90° steel manual insert (15/16) Angled insert (1/16)

^a All pumps were funded by PHARMAC, Pharmaceutical Management Agency of New Zealand;

Table 2 Training and education details

	Participants (n = 16)
Pump starts / y, median (range)	6 (2–22)
Current wait list (months), median (range)	0 months (0–18)
In-patient vs Out-patient	Out-patient (14/16) In-patient (2/16)
Total duration (h)	7.5–21
Patients per pump start	Individual (11/16) Groups (5/16) ^a
Predominant educator	Company (16/16) (Supplementary team support)
Proportion of local team input	10–50%
Printed resources provided	Mixed - company and local team design
Insulin dose calculations/reductions (basal dose)	20–30% reduction from MDI TDD
Basal profile	Variable (14/16) Flat (2/16)
Insulin commencement via the pump	Day 1
Rapid acting insulin preference	Novorapid (12/16) Same as injection regimen (4/16)
Smart/advanced feature use, days	Variable (1–28)

^a Average number of patients in group sessions was 2 patients ($\pm$ their carers), with a maximum of 4 patients; MDI, multiple daily injections; TDD, Total daily dose

unofficially “on-call” for the period of the pump start. The remaining hospitals directed patients to either the pediatric registrar, endocrinology fellow (1/16), or pediatrician on call.

Discussion

This is the first study to specifically investigate current insulin pump initiation with regard to education and training. The findings highlight variation in pump education practice within New Zealand. A lack of guidance and evidence base from the medical literature likely contributes to this variation. In addition, variations on resourcing, as well as the motivations and beliefs expressed relating to these various pump start approaches also varied, demonstrating team preference and differing interpretations of the available literature. This sort of variation in clinical paediatric diabetes practice has been observed in other core aspects of care such as insulin regimen decisions at new diagnosis and beyond [15, 16].

The results obtained in this study show that the majority of teams in New Zealand have moved away from inpatient insulin pump initiation. Anecdotally variation between in- and outpatient pump initiation is seen around the world. Other than cost saving, a major motivation for conducting insulin pump starts in the outpatient setting was an effort to maintain the patient as close to their own environment as possible, including eating their usual food and doing their usual day to day activities, all factors that may give a better representation of patient routine, glycaemic control, and glucose variability throughout the day [17]. Furthermore, with the availability of CGMS it has become easier for patient monitoring to be achieved safely at home (as utilised by teams in our results), and insulin doses rapidly adjusted in response. No data currently exists regarding safety of the approaches described in this work. However, outpatient practice was anecdotally reported as safe, and would be in line with the current practice of some hospitals to conduct general education of newly diagnosed diabetes patients in an outpatient setting, with no hospitalisation occurring at all [15].

Table 3 Post education monitoring and follow up

	Participants (n = 16)
Concurrent CGMS and duration of use	Yes, 7–14 days (12/16) No (4/16)
Use of pump data management programme (Diasend/Carelink)	Yes (16/16)
Refresher classes	No (11/16) Ad-Hoc (5/16)

With regards insulin pump smart features, the impact of delayed use and its overall contribution to safety is unknown, but it has been found that many patients using insulin pumps find manually calculating bolus insulin doses challenging [18]. Difficulties with calculating bolus doses may lead the patient to administer fixed bolus doses or even adopt a carbohydrate restricted diet [18]. In a study of 104 participants, which compared the use of smart features with manual calculation of insulin doses, an error rate of 63% was seen when insulin doses were calculated manually, which ultimately affected glycaemic control and efficacy of the insulin pump therapy [18]. All of the above factors would suggest early initiation of smart features may offer a safety advantage, and should certainly be considered.

Finally, a common theme stated by participants was that patients and their families tend to be given a lot of new information during these short pump education sessions. This is important to bear in mind, as like any other device, insulin pumps are prone to incorrect use as well as forgotten concepts. This can lead to adverse events and potentially impact glycaemic control. It is therefore interesting that refresher education was either ad-hoc or not done at all for all participating centres. This goes against current recommendations which suggest opportunistic refresher education should occur when switching from one model insulin pump to another or for any pump upgrade, as well as periodically for all patients and caregivers utilising pump therapy to ensure both safe and optimal use [19].

Strengths of this study are: 1) the use of in-depth structured interviews, allowing a greater depth and quality to the information regarding current practice collected, and the clarification of subtle variations seen; and 2) the high response rate, where a 100% response was achieved for the selected paediatric teams. There are also a number of limitations. Only one DNS from each team was interviewed with their responses taken as representative of their hospital practice, therefore the data collected may contain errors due to recall bias. In addition, only a publicly funded model of care is examined, as this is the only model available in New Zealand. Finally, our data is unable to provide concrete recommendations on the various approaches used. Nor can it provide information on patient outcomes of these different approaches.

Conclusion

In conclusion, variations in practice exist within New Zealand hospitals with respect to core aspects of insulin pump education and support. This lack of consistency between hospitals likely reflects individual clinician opinion, as well as a lack of consensus/guidance from the medical literature. Further rationalisation and improvement in education approaches is

likely possible by combining and adopting strengths from these different hospital approaches. This may be applicable not only in New Zealand but to the wider international community. Further research is needed to explore outcomes such as safety, glycaemic control, and patient satisfaction resulting from these differing educational approaches.

Acknowledgments The authors wish to thank all the participants and the Paediatric Society of New Zealand Diabetes Clinical Network for their time and assistance with this study. The authors would also like to thank the School of Pharmacy, University of Otago, Dunedin, New Zealand for the funding given to carry out this project.

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References

1. The Effect of Intensive Treatment of Diabetes on the Development and Progression of Long-Term Complications in Insulin-Dependent Diabetes Mellitus. *N Engl J Med*. 1993;329(14):977–86.
2. Danne T, Bangstad H-J, Deeb L, Jarosz-Chobot P, Mungaie L, Saboo B, et al. Insulin treatment in children and adolescents with diabetes. *Pediatr Diabetes*. 2014;15(S20):115–34.
3. Silverstein J, Klingensmith G, Copeland K, Plotnick L, Kaufman F, Laffel L, et al. Care of children and adolescents with type 1 diabetes a statement of the American Diabetes Association. *Diabetes Care*. 2005;28(1):186–212.
4. Craig ME, TS, Donaghue KC, Cheung NW, Cameron FJ, Conn J, Jenkins AJ, Silink M, for the Australian Type 1 Diabetes Guidelines Expert Advisory Group. National evidence-based clinical care guidelines for type 1 diabetes in children, adolescents and adults. Canberra, Australia: Australian Government Department of Health and Ageing; 2011.
5. Pankowska E, Blazik M, Dziechciarz P, Szypowska A, Szajewska H. Continuous subcutaneous insulin infusion vs. multiple daily injections in children with type 1 diabetes: a systematic review and meta-analysis of randomized control trials. *Pediatr Diabetes*. 2009;10(1):52–8.
6. Misso ML, Egberts KJ, Page M, O'Connor D, Shaw J. Continuous subcutaneous insulin infusion (CSII) versus multiple insulin injections for type 1 diabetes mellitus. *Cochrane Database Syst Rev* 2010(1):CD005103.
7. Cooper MN, O'Connell SM, Davis EA, Jones TW. A population-based study of risk factors for severe hypoglycaemia in a contemporary cohort of childhood-onset type 1 diabetes. *Diabetologia*. 2013;56(10):2164–70.
8. Wheeler BJ, Heels K, Donaghue KC, Reith DM, Ambler GR. Insulin pump-associated adverse events in children and adolescents—a prospective study. *Diabetes Technol Ther*. 2014;16(9):558–62.
9. Ross P, Milburn J, Reith D, Wiltshire E, Wheeler B. Clinical review: insulin pump-associated adverse events in adults and children. *Acta Diabetol*. 2015;52(6):1017–24.
10. Wheeler BJ, Donaghue KC, Heels K, Ambler GR. Family perceptions of insulin pump adverse events in children and adolescents. *Diabetes Technol Ther*. 2014;16(4):204–7.
11. Bode BW, Kaufman FR, Vint N. An expert opinion on advanced insulin pump use in youth with type 1 diabetes. *Diabetes Technol Ther*. 2017;19(3):145–54.

12. Scheiner G, Sobel RJ, Smith DE, Pick AJ, Kruger D, King J, et al. Insulin pump therapy guidelines for successful outcomes. *Diabetes Educator*. 2009;35(2 suppl):29S–41S.
13. Swift PGF. Diabetes education in children and adolescents. *Pediatr Diabetes*. 2009;10:51–7.
14. PHARMAC. Funding of New Zealand Medical and Scientific Insulin pump and consumables approved 2012 [cited 2016 02 June]. Available from: <http://www.pharmac.govt.nz/2012/08/08/Insulin%20pumps%20notification.pdf>. Accessed 02 June 2016.
15. Selvakumar D, Al-Sallami HS, de Bock M, Ambler GR, Benitez-Aguirre P, Wiltshire E, et al. Insulin regimens for newly diagnosed children with type 1 diabetes mellitus in Australia and New Zealand: a survey of current practice. *J Paediatr Child Health*. 2017;53(12):1208–14.
16. Phelan H, Clapin H, Bruns L, Cameron FJ, Cotterill AM, Couper JJ, et al. The Australasian diabetes data network: first national audit of children and adolescents with type 1 diabetes. *Med J Aust*. 2017;206(3):121–5.
17. Ludvigsson J, Hanas R. Continuous subcutaneous glucose monitoring improved metabolic control in pediatric patients with type 1 diabetes: a controlled crossover study. *Pediatrics*. 2003;111(5):933–8.
18. Sussman A, Taylor EJ, Patel M, Ward J, Alva S, Lawrence A, et al. Performance of a glucose meter with a built-in automated bolus calculator versus manual bolus calculation in insulin-using subjects. *J Diabetes Sci Technol*. 2012;6(2):339–44.
19. Grunberger G, Abelson JM, Bailey TS, Bode BW, Handelsman Y, Hellman R, et al. Consensus statement by the American Association of Clinical Endocrinologists/American College of Endocrinology insulin pump management task force. *Endocrine practice : official journal of the American College of Endocrinology and the American Association of Clinical Endocrinologists*. 2014;20(5):463–89.