

Experiences and decision making during paediatric transitions to continuous sub-cutaneous insulin infusion (CSII): A mixed method study

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Erika Altmann¹, Christine Stirling²  and Liz Broad³

Abstract

Objectives: We aimed to improve the decision quality and outcomes for families with children or adolescents with diabetes considering continuous sub-cutaneous insulin infusion (CSII).

Methods: A mixed method study involved three focus groups with youth, parents and clinicians to provide experience information as background to the development of a decision aid (DA). A pre-test (T1) and post-test (T2) evaluation of the DA with a convenience sample of five families considering initiating CSII.

Results: The focus group data showed that families found the move to CSII to be generally empowering with adolescents engaging with the technology quickly, and that experiential information from others was important in the process. Participants increased their knowledge and decreased decisional conflict after using the DA from T1 to T2. Preferred option measurement indicated that at T1, three participants were 'unsure' and two participants' preferred option was CSII. After exposure to the DA at T2, those who were previously unsure had a preferred option of CSII with a resulting five people with a preferred option of CSII.

Conclusions: The results from this study suggest that transitioning to CSII for paediatric and adolescent patients and their carers may be assisted by a DA and that participants felt empowered to make a decision regarding CSII when using the PANDANI DA. The quasi-experimental design without randomisation or control group was a study limitation caused by the small number of participants. Expanding this pilot research into a randomised control trial would decrease the threat to validity from other possible explanations for the improvement in decisional conflict, such as nurse educators.

Keywords

Insulin pump therapy, CSII, type 1 diabetes, paediatric, decision aid, nurse educators

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Introduction

The incidence of diabetes is increasing in Australia and around the world¹ with 5.1% of Australian children aged 14 years and under diagnosed with type 1 diabetes (T1D) and two-fifths of these placed on insulin pump therapy.² Little is known though about how families of children with T1D cope with the transition to more intensive and high-tech management, and whether decision support influences their choices around continuous sub-cutaneous insulin infusion (CSII). We report

¹School of Social Sciences, University of Tasmania, Hobart, Australia

²School of Health Sciences, College of Health and Medicine, University of Tasmania, Hobart, Australia

³Women, Adolescent and Children and Services, Department of Health & Human Services, Hobart, Australia

Corresponding author:

Christine Stirling, School of Health Sciences, College of Health and Medicine, Private Bag 35, University of Tasmania, Hobart, Tasmania 7000, Australia.

Email: Christing.stirling@utas.edu.au

Twitter: @CMStirling1



the outcomes of the Paediatric and Adolescent iNsulIn pump Decision Aid Project (PANDANI) that aimed to understand the transition experience to CSII and to improve the decision quality and outcomes for families through the development and piloting of a decision aid (DA).

Decision support involves providing information to improve knowledge and awareness of resources to enable realistic expectations. DAs assist clarification of values and help people develop a sense of efficacy when making choices.³ Decisional regret is associated with poorer quality of life after treatment for serious illnesses such as cancer, with under-informed patients being at greater risk of regret.³ Using DAs, people may feel more confident in making a timely choice, experience less decisional conflict, less delay in making decisions, less decisional regret, and fewer discontinued decisions.^{4,5} DAs are particularly useful in complex situations where outcomes may involve trade-offs between risks and benefits, or when choices are dependent more on values and beliefs than outcomes. Unlike educational materials, they focus on options in a specific and personalised manner that facilitates decision making and empowers people to synthesise information and preferences so that they can make informed and person-centred health care decisions.

Intensive diabetes management leads to improved glycaemic control and a reduction in diabetes-related complications.⁶ To achieve this with traditional treatment options requires multiple injections of insulin every day plus multiple finger-prick testing for blood glucose levels (BGLs).⁷ CSII instead involves wearing a small electronic device that delivers insulin subcutaneously via a cannula with pre-programmed doses. The cannula requires changing every 2–3 days, thereby decreasing the ‘injections’.

CSII provides greater lifestyle flexibility in food choices and activity with less risk of BGL outside the optimal range. However, there is less evidence of the benefits of CSII in paediatric populations when compared to adult populations, though research indicates that CSII improves outcomes and quality of life.^{1,8} Study results are somewhat mixed but have demonstrated the efficacy of CSII in decreasing hypoglycaemia⁹ and achieving near-normoglycaemia in children^{10–12} compared with traditional injections. This is important because normoglycaemia helps to prevent acute and chronic metabolic complications, life-threatening diabetic ketoacidosis or severe hypoglycaemia leading to coma, seizure and/or death.¹³ Apart from the insulin delivery function, CSII allows data storage for BGLs, insulin doses, exercise and diet, and interacts with software that provides data analysis. CSII technology is rapidly improving and new devices

may have increased safety measures to prevent hypoglycaemia.

Despite the many benefits of CSII, there are a number of variables that affect successful uptake and discontinuation rates. An evaluation in Ontario found large variation in uptake of funded CSII in children, greater discontinuation rates and a higher risk profile for lower socioeconomic groups.^{14,15} Importantly, there is a greater risk of discontinuation of pump use during the first year of use,¹⁶ with puberty, or being female, implicating peer pressure and negative body image issues.¹¹ Adolescents and families have also reported periodic discontinuation of CSII during holiday periods and other ‘break periods’.^{8,16} For some, discontinuation of CSII among these groups has been attributed to a poor client match, as some clients may not have the capacity to manage the procedures of CSII.¹⁷ In some instances, CSII is also associated with more rapid rates of ketoacidosis when compared with injection therapy, a greater need for trained personnel and high upfront costs of pumps.^{9,18}

For children considering CSII, the choice between injection therapy and CSII needs to account for the family and school context as well as the child and clinician perspectives in order to account for the known success factors.¹⁵ In the case of children using CSII, needing to reverse an uptake decision quickly may leave the child and/or family with a negative view of CSII treatment and an unwillingness to return to it at a more appropriate life stage, particularly where the cost of pumps are a major consideration.¹⁷

Over 500 aids have been developed globally and DAs are now being viewed as a useful means to help those with chronic conditions to make complex and family-based decisions.³ Due to the complexity of multiple players in a child’s life, and the complexity of factors affecting uptake and discontinuation, creating a targeted DA for child and adolescent populations when considering CSII appears a natural step. This paper describes the experience of youth, parents and clinicians in the transition to intensive technological CSII, and the development feedback and piloting of a DA for children and families considering CSII.

Methods

A mixed method study developed and evaluated the DA with participatory input from paediatric and adolescent patients and their families between 2014 and 2016. A review of literature identified the known correlates of CSII success and failure, in order to encapsulate these into the DA. Focus groups were used to assess decision-support needs through understanding the experiences of young adults and parents who had previously adopted CSII and feedback about the draft

DA. The study then used a one-group pre-test–post-test to evaluate the DA, which involved five families from two sites within Tasmania, a state of Australia.

Three focus groups were held with one each for clinicians, parents and young adult CSII users. Focus groups are a useful way to understand diabetes-related phenomena and develop interventions such as DAs.¹⁹ Participants for the focus group were recruited through advertisements with the clinician professional bodies, the key diabetes centres, and word of mouth, with those interested contacting the researchers. People under the age of 18 were excluded from the interview stage. A semi-standardised set of questions (Table 1) asked about the experience of transitioning to pump, issues affecting decisions to use CSII, and feedback on the draft DA.

Focus group 1 comprised two diabetes educators and one paediatric registrar. Together, the three female participants managed approximately 200 paediatric and adolescent patients through diabetes clinics.

The participants related their comments exclusively to the under-18-years age group. The second focus group comprised six parents, all female. The age of their children with T1D ranged from 2–15 years and they had been diagnosed at least 1 year previously. The children had various trajectories to CSII. Four of the children had been on CSII for at least 3 years. One adolescent had previously tried CSII, discontinued, then reconnected to CSII within the previous 6 months. A second adolescent had begun CSII 3 weeks previously. One preschool aged child had been placed on CSII soon after diagnosis. The third focus group contained two youths aged between 18 and 20 years who had moved to CSII at the age of 14–15 years. Limitations in ethics approval precluded our ability to interview children and adolescents under the age of 18 years. Feedback from the focus groups was used to develop the PANDANI DA.²⁰

A pre-test (T1) and post-test (T2) evaluation of the DA was conducted with a convenience sample of five

Table 1. Focus group questions.

| | |
|----|--|
| 1 | Introductions, participants may choose to use a pseudonym. |
| 2 | Participants are asked the following information: a. Age and age of child if relevant b. Relationship to child with type 1 diabetes – parent/guardian/clinician/teacher c. Sex – M/F d. Date of diagnosis if relevant. |
| 3 | Briefly tell me what each of you understand by type 1 diabetes. |
| 4 | Going around the group again, how did you first become aware of type 1 diabetes and what were your first personal interactions with a child/adolescent with type 1 diabetes. |
| 5 | What is your experience of insulin pump therapy, and what involvement did you have (e.g. parent helping or using pump, teacher, child using pump)? |
| 6 | In your experience, how do treatment processes affect the lives of children and families? (Prompt: regarding insulin pump or regular injections, blood testing.) Prompt: What are the positives and the negatives? |
| 7 | In your opinion, which factors make insulin pump therapy successful? |
| 8 | In your opinion, which factors make insulin pump therapy difficult? |
| 9 | In your experience, what information and support would help children/families to cope with insulin pump therapy? Prompt: How well do you feel that the current information meets these needs? |
| 10 | Considering the decision aid: a. Is there additional information which needs to be added to adequately reflect your experiences in moving to pump therapy? b. Is there information which you consider would be better off removed from the decision aid? c. Are there changes that you would make to the format or set out of the decision aid to increase readability and helpfulness? |

families where the children/adolescents and parents were considering initiating CSII, recruited between August 2016 and November 2016. The project was advertised through the state's three diabetes centres with 16 initial enquiries resulting in eight families consenting. Only five families completed the trial, one with a child under 5 years of age, two with primary school aged children and two with adolescents. Inclusion criteria for patients were: the child/adolescent had T1D, the child/adolescent was not already on an insulin pump, the family or child/adolescent was open to the idea of an insulin pump, the child/adolescent was under the age of 18 years and the child/adolescent and family's written and spoken English language skills were sufficient to exclude the need for an interpreter.

After obtaining informed consent, a researcher administered the T1 questionnaire via phone link. The T2 questions were administered approximately 6 weeks later. This interval period gave families time to meet with their diabetes educator and also to use the DA in a variety of situations. Five families completed both T1 and T2. Standard demographic information was collected. Ten diabetes knowledge questions using five child-appropriate general diabetes knowledge questions from the Michigan Knowledge Scale²¹ and five insulin pump knowledge questions tested from the Agency for Healthcare Research and Quality (AHRQ)²² were collected using true/false/don't know responses. The Decision Conflict Scale (DCS)²³ and questions about preferred choice (fixed dose injections, multiple daily injections, insulin pump therapy, and not sure) measured decision making. In the T2 intervention an additional set of three questions were asked that related specifically to the use of the DA intervention.²⁴

Analysis

Focus group data were transcribed and thematically analysed using inductive analysis and categorisation. Descriptive characteristics for children and parents are reported in Table 2 and changes in knowledge were treated as T1 and T2. The DCS scores were converted to a 0–100 scale. Paired *t*-tests (two-sided and CI > .095) were used to compare mean changes in scaled measurements of decisional conflict from T1 to T2. Knowledge answers were converted to dichotomous correct/incorrect answers.

Focus group findings

The focus group data showed that families found the move to CSII to be generally empowering, with adolescents engaging with the technology quickly. Both clinicians and parents of children with diabetes felt a DA

Table 2. Demographic information for trial participants.

| | Count |
|---|-------|
| Parent gender | |
| Male | 0 |
| Female | 5 |
| Child gender | |
| Male | 4 |
| Female | 1 |
| Child age in years | |
| Less than 5 | 1 |
| 5–12 | 2 |
| 13–15 | 2 |
| Australian born | |
| Child | 5 |
| Highest education level: parent | |
| Grade 10 | 1 |
| Trade Certificate | 2 |
| University Bachelor | 2 |
| Financial stress measure (can you get \$2000 within 7 days?) | |
| Yes | 3 |
| No | 2 |
| Clinic relationship | |
| Mother | 3 |
| Father | 0 |
| Both parents | 2 |

Note: This research was supported through a competitive grant.

would be useful, and provided feedback on the final draft of the DA.

Decision motivation: less needles and flexibility

The young adults reported that as adolescents they had felt empowered by the flexibility that the pump offered,

though this was not their primary consideration for moving to a self-tracking device.

I came in for my usual check up and went home with a pump on order ... I suppose that it was a little unusual but my overriding thought was less needles. I was sick of the needles ... It wasn't really until after I got the pump that I realised how good it was. I was a teenager and for the first time I could sleep in (Youth, Participant 1).

Our young adult participants reported that as adolescents the flexibility CSII provided included simple pleasures such as staying up late and being able to sleep longer in the morning.

Transition to new technology CSII

The two youth reported being proud of their pump. It was something new that everyone wanted to engage with.

It was like a toy. I enjoyed getting to know how it worked and what the best way to do things was (Youth, Participant 1).

I remember being proud and self-conscious at the same time. It was a bit like show and tell. My family all wanted to have a play with it (Youth, Participant 2).

As adolescents, they adapted easily to the new technology and felt they really understood the implications of their pump readings.

I was flying within a few days. It took a week at most to work out what to do with it (Youth, Participant 2).

All focus group participants spoke about the need for adequate support and education prior to adopting CSII.

So we push questions at young people and we say ... imagine you've got a pump on and I want you to write up all the questions that come up – you're having a shower, you're having a meal, playing footie, ... what comes up? (Clinician, Participant 1).

Clinicians concentrated on the child and the provision of factual information for child and parent. Examples included teaching carbohydrate counting and what to do if the set falls out.

We take them through all the basics ... Set changes ... Then there is the technical stuff as ... how to problem solve (Clinician, Participant 2).

Avenues of support and information

Parents and clinicians identified a need for more experiential information in preparing them for the intense pressure at the initial change over to CSII. In addition to the information provided by diabetes educators and their paediatricians, parents wanted to discuss the decision with people who had lived through the experience.

I think we had lots of information and everyone kept telling us, ... 'It's like relearning diabetes all over again'. ... But that's probably not very useful just saying that without anything else. You know even saying things like 'have you thought about the practicalities'. I'm back to the meal preparation again. You know, freezing some food, because I wish I had done that (Carer, Participant 3).

Parents acknowledged that they received a significant amount of information about CSII and the pump. They received training about CSII, but were unprepared for the mental and physical strain from transitioning their child to CSII. They were unprepared for the rigours of sleepless nights, the increased number of finger pricks and CSII monitoring on a 24-hour basis along with the need to absorb new information, count carbs and address issues raised by third parties such as schools.

I never saw it coming. I didn't think I would ever feel this low ... I'm crap and my husband's crap at the moment and we're just three weeks in. [Child's]s back at school and he's looking like crap. Pump's going really well though (Carer, Participant 2).

Clinicians reported that there was a greater ability to problem solve with children/adolescents using CSII and their parents because they could look through the data sent to them without the need for scheduled patient appointments. Combined with telephone calls, the overall participation between clinicians and patients increased and appointment time decreased. Though there are other formal organisations that support people with diabetes and their families such as Diabetes Australia, these were not mentioned as a source of information, support or help in moving to CSII. Overall, parents felt a need to hear first-hand stories of the CSII journey from other parents who understood the challenges of life with CSII.

Ensuring collaborative decision-making. Clinicians wanted children to identify their treatment preference early in the decision process to ensure the child wanted a

Table 3. Decisional conflict scores and subscores.

| Scale ^a | Pre-test, mean \pm SD | Post-test, mean \pm SD | <i>P</i> (paired <i>t</i> -test) |
|---------------------------|-------------------------|--------------------------|----------------------------------|
| Decision Conflict Scale | 33.13 \pm 16.96 | 15.62 \pm 10.88 | 0.02 |
| Uncertainty | 51.67 \pm 33.02 | 18.33 \pm 16.03 | 0.05 |
| Support | 26.67 \pm 18.07 | 15.00 \pm 18.07 | 0.14 |
| Effectiveness of decision | 26.25 \pm 15.56 | 13.20 \pm 9.99 | 0.01 |
| Value clarity | 26.67 \pm 10.86 | 13.33 \pm 12.64 | 0.02 |
| Informed | 36.67 \pm 17.27 | 15.00 \pm 9.13 | 0.03 |

Note: ^aScores range from 0 (no decisional conflict) to 100 (extremely high decisional conflict). Scores >37.5 are associated with decision delay or feeling unsure and scores <25 are associated with implementing decisions.

treatment change. In some cases, parents initiated CSII even though the child did not want it.

There was some question as to whether she really wanted a pump. She is six years of age but from the family point of view the pump was the best choice. This young person we believe has been sabotaging her pump and has now come out and said ‘I really don’t want the pump’ (Clinician, Participant 1).

This story highlights the potential to disempower children in planning treatment and the importance of clinicians engaging with the child’s wants as well as the carers’.

Engagement with third parties such as schools, day-care, sporting clubs or other extra-curricular activity groups also occupied much of the carers’ time. Moving to CSII intensified their involvement with these groups as the change in treatment regime needed to be explained to them. Carers reported varying degrees of acceptance and support from these groups.

Following the focus groups, changes were made to the DA. These changes included formatting changes, the inclusion of additional information and additional questions into the decision-making process. All focus group participants suggested an electronic version of the DA would be useful. The adolescent focus group advised that they would not use a paper-based DA, whereas the carer and clinician focus groups indicated the value in having both a paper-based and electronic version, particularly where they needed to engage with third parties such as schools and day-care.

Decision aid evaluation results

Participants increased their knowledge and decreased decisional conflict from T1 to T2. Preferred option

measurement indicated that at T1, three participants were ‘unsure’ and two participants’ preferred option was CSII. After exposure to the DA at T2, those who were previously unsure had a preferred option of CSII with a resulting five people with a preferred option of CSII.

As shown in Table 3, the mean score for the DCS significantly decreased after exposure to the DA, with participants moving into the score range associated with implementing decisions (<25). All subscales, apart from Support, decreased post intervention ($p < 0.05$). The subscale Uncertainty reflects items ranging from ‘feels extremely certain about best choice’ (score 0) to ‘feels extremely uncertain about best choice’ (score 100). The Uncertainty results showed the largest decrease in mean scores ($p < 0.05$). All participants demonstrated a decrease in DCS, even those who did not change their preferred option.

The general diabetes knowledge questions were answered correctly pre intervention (with the exception of one question: 2% incorrect) but 22% of the CSII-related questions were incorrect. Table 4 shows the T1 and T2 answers to the five insulin pump knowledge questions with only 6% of answers incorrect. The response ‘I don’t know’ was treated as incorrect.

Discussion

This research highlights the potential of CSII as empowering technology. Empowerment is the social process of recognizing, promoting, and enhancing people’s abilities to meet their own needs and problem solve those issues through the mobilisation of resources.²⁵ The acquisition and development of these resources and the ability to use them to problem solve and enhance self-determination brings about a state of wellness. While the transition to CSII was more intensive,

Table 4: Diabetes Knowledge test results T1 and T2.

| Question | Code | Correct T1 | Incorrect T1 | Correct T2 | Incorrect T2 |
|--|---------|------------|--------------|------------|--------------|
| | | Count | Count | Count | Count |
| Insulin pump therapy will make me gain weight | K3.6T1 | 4 | 1 | 4 | 1 |
| I can detach from my pump for up to two hours provided I remember to bolus | K3.7T1 | 1 | 4 | 4 | 1 |
| Insulin pumps are bulky and uncomfortable to wear | K3.8T1 | 3 | 2 | 4 | 1 |
| My eating times will be rigid if I use insulin pump therapy | K3.9T1 | 4 | 1 | 5 | 0 |
| I will not need to monitor blood glucose levels if I get an insulin pump | K3.10T1 | 4 | 1 | 5 | 0 |
| Total | | 39 | 11 | 44 | 6 |

it was seen as empowering because it gave children, families and clinicians timely information and allowed a more flexible, normal, lifestyle. Clinicians provided extensive support and information, but parents also wanted peers' experiential information to help them prepare and cope with the physical and emotional demands of moving to CSII.

The T1 and T2 DA intervention results suggest that the DA provided decision support for those parents and children who were making a decision about CSII. While the small purposive sample size and the lack of a control group limit the conclusions that can be drawn from this study, the change in scores from the well-validated DCS, do indicate that the participants moved from a state of decisional conflict, with scores associated with decision delay, to a state associated with implementing decisions. The decrease in scores also suggests that participants may be less likely to change their minds, express decisional regret, and blame their doctor or clinician for bad outcomes.²⁶ Given the complexity of the change to CSII, the use of a structured decisional aid is recommended. Expanding this pilot research into a full RCT would be useful to further examine the effect of the PANDANI DA in this growing patient population. The pilot study has also demonstrated that recruitment of participants into this type of study would require additional strategies, and that an electronic version of the DA would be the preferred medium. Electronic DAs have been found to be beneficial in other circumstances.²⁷

The findings from this research provide insight into the transition experience of the participants. However, recruitment difficulties meant that the small number of participants in two of the focus groups limited the analysis. Recruitment difficulties also meant that two of the focus groups contained only women. While families engaged in the research had some diversity in terms of economic status and educational attainment, it is clear that they all provided a supportive environment for diabetes management. It is possible that less supportive environments may need additional strategies.

Strengths and limitations

This DA has been developed and strengthened through a mixed method approach, which provided qualitative perspectives. Results suggest further research is needed that measures empowerment outcomes for children and adolescents.

The quasi-experimental design without randomisation or control group was a study limitation resulting from the small number of participants. Expanding this pilot research into an RCT would decrease the threat to validity from other possible explanations for the improvement in decisional conflict, such as nurse educators. The pilot study has also demonstrated that recruitment of participants into this type of study would require additional strategies. Development of an electronic version of the DA was suggested by the Advisory Group and focus group participants.

Conclusion

CSII is a management device that may be used to manage and reduce diabetes-related complications. In this research, paediatric and adolescent patients and their carers reported adapting well to CSII and received benefits over and above the medical health benefits sought from better management of BGLs.

The results from this study demonstrate that a DA may assist the decision to adopt CSII for paediatric and adolescent patients and families. Children, families and clinicians reported feeling empowered by the dual-level data collection of CSII leading to increased interactions around diabetes management. For this to occur, clinicians need to ensure that children are involved in the decision to change to CSII, whilst taking into account overall family needs.

The research also found that the clinician focus is on the patient rather than carer during the transition process. Though parents were engaged with the process of moving to CSII, parents did not feel that they were adequately supported with practical help and tips needed to ensure optimum carer self-care during the transition period. Our DA filled this gap, but diabetes educators could also work to improve peer-support information for families.

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Guarantor: CS

ORCID iD

Christine Stirling  <http://orcid.org/0000-0003-2723-8302>

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