Young people with type 1 diabetes: attitudes, perceptions and experiences of diabetes management and continuous subcutaneous insulin infusion therapy

RUNNING TITLE:
Young people with type 1 diabetes

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CONFLICTS OF INTEREST:

None.
ABSTRACT:

Rationale, aims and objectives

Continuous subcutaneous insulin infusion (CSII; insulin pump) use is increasing. However, there is little information about how this technology is used compared to other insulin delivery methods (i.e. injections) by young people with type 1 diabetes in Australia. This study explored young people’s attitudes, perceptions and experiences with diabetes management comparing those using and not using CSII, and proportions likely to transition to adult services requiring initiation and/or support for CSII use.

Methods

A survey was undertaken of young people (aged 12 - 18 years) with type 1 diabetes and their parents/guardians living in Hunter New England, Australia, using a questionnaire designed to collect quantitative, descriptive and demographic data. Most questions were based on previously developed and validated instruments. In total 107 respondents returned partially or fully completed questionnaires.

Results

Respondents had positive attitudes and perceptions of their self-efficacy and diabetes management, but were moderately disturbed by their diabetes and reported experiencing sub-optimal management outcomes. Patterns of associations were demonstrated between knowledge, attitudes and experiences of diabetes modelled by regression analysis. There were no statistically significant differences in responses between users and non-users of CSII. Over 40% indicated their intention to use the technology as adults.

Conclusions
Opportunities for enhanced diabetes service support were clear, and CSII did not appear to be used to its full potential. Service redesign could enhance support for this young population using all preferred insulin delivery methods, and should align to patients’ goals and preferences to maximise service and patient gain.
INTRODUCTION:

More than two decades ago the landmark Diabetes Control and Complications Trial\(^1\) established that the onset and progression of micro-vascular complications in type 1 diabetes
(T1D) can be significantly reduced by tight glycaemic control. As a method of insulin
delivery continuous subcutaneous insulin infusion (CSII; insulin pump) therapy offers
potential towards achieving this. Clinical and quality of life improvements have been
demonstrated for some children and adults\(^2\)-\(^{12}\); however, living with CSII is not without
challenges. Device malfunction and infusion set/site failures are not uncommon and may
increase hypoglycaemia or ketoacidosis risk; CSII use has been reported to increase
Emergency Department (ED) presentation rates\(^{13}\)-\(^{15}\).

Australian data indicate a consistent increase in rates of CSII commencement\(^{16}\). By 2011
around 10\% of this T1D population were using this technology\(^{16}\), broadly similar to data
from Sweden, the Netherlands and Germany\(^{17}\), though lower than that reported in the United
States\(^{18}\),\(^{19}\). A high proportion of CSII users in Australia are young people; one third of people
with type 1 diabetes in Australia aged under 20 years use CSII technology. 40\% of all new
users between 2008 - 2010 were under 18 years of age\(^{16}\). This represents a large number
considering more than half of all new cases of type 1 diabetes occur in people aged under 18
years, with rates three times as high among 0 - 14 year olds (24 per 100,000 population)\(^{20}\).

Australian CSII uptake may have been influenced by the introduction of a government
subsidy for low income families with children with T1D in 2008\(^{21}\). The sum of Au$6,400 (or
80% of the device cost) may be available to persons with type 1 diabetes aged under 18 years that have an annual family income under Au$73,146 or receive government income support payments; varying support with the 20% co-payment is available for those that qualify for the maximum device subsidy. Besides personal finance, CSII devices in Australia may also be obtained through private health insurance, clinical trial enrolment, or through charitable donations. The majority (89%) of CSII users receive financial assistance to acquire their device, with almost all of these (97%) using private health insurance\textsuperscript{16}. The consequence of this method of purchase is that usage is more commonplace in higher socio-economic areas (14% versus 6%)\textsuperscript{16}. Regardless of age, the consumables needed for patients with type 1 diabetes to use CSII technology are subsidised by the Australian Government, subject to eligibility criteria\textsuperscript{22}.

Despite increasing CSII use, there is little Australian information about the everyday experiences of young people with T1D, or their intentions towards CSII use once they become adults. The aim of this study was to explore young people’s attitudes, perceptions and experiences with diabetes management, comparing those using and not using CSII (i.e. delivering insulin via injections); and to estimate the proportion likely to transition to adult services requiring initiation and/or support for CSII use.

METHODS:

This was a cross-sectional survey conducted in collaboration with Hunter New England Local Health District (HNELHD), the public healthcare provider for around 850,000 residents.
across 130,000 square kilometres of metropolitan, regional and rural New South Wales (NSW), Australia. Approval was obtained from Hunter New England (HNE) Health and University of Newcastle Human Research Ethics Committees.

Young people aged 12 - 18 years with T1D and their parents/guardians residing within the HNE region, were identified through a HNELHD clinical database in 2011. All had access to specialist diabetes care either through attendance at a specialist multi-disciplinary diabetes service located at a tertiary metropolitan children’s hospital, or through their regular specialist paediatric outreach program. Initial contact came from recipients’ diabetes nurse educators. Packages of introductory letters, information statements, consent forms and the questionnaire were posted to the address recorded in case records. Recipients were asked to return a signed consent form and completed questionnaire in the included stamped, addressed envelope. In the event of no response one reminder package was posted.

The questionnaire was constructed by research team members and reviewed by local diabetes clinicians. Most questions were derived from or based on previously developed and validated instruments. The questionnaire contained the Perceived Diabetes Self-Management Scale (PDSMS), an eight-item uni-dimensional measure of self-perceived diabetes self-management efficacy scored as a five-point Likert-type scale (1 = Strongly disagree, 5 = Strongly agree). This measure has previously demonstrated construct, discriminant and predictive validity, and in this study a Cronbach alpha of .92 indicated internal consistency.
Perceptions of disease knowledge, self-care independence and sense of disturbance (upset or annoyance) caused by diabetes were measured using four questions developed by Viklund et al.\textsuperscript{25} Responses were via visual analogue scales ranging from 0 - 100 mm with five anchor points; higher scores indicated greater knowledge, independence and disturbance, scaling from ‘Nothing’ to ‘Everything’ (knowledge) and from ‘Never’ to ‘All the time’ (other items).

Demographic data were sought, and residential area was categorised according to the Australian Standard Geographical Classification\textsuperscript{26}. Questions sought diabetes-related clinical data to augment identification of young people’s experiences, including self-report of HbA1c values, hypoglycaemic episodes, diabetes-related ED presentations and hospital admissions, and the occurrence of ophthalmic examination and urine checks for renal disease within the past year. Three closed questions enquired about episodes of CSII dysfunction or discontinuation, and two questions sought to estimate the proportion of paediatric patients transitioning to adult services in the next five years likely to require CSII initiation, on-going support and monitoring.

Quantitative data were entered into SPSS Version 22 software for analysis and all test and model assumptions were checked and met. Comparisons were drawn between CSII users versus non-users using appropriate analyses. Four PDSMS items\textsuperscript{24} were reverse-coded prior to summation of the eight-item measure. Data for the PDSMS items, perceptions of disease knowledge, self-care independence and sense of disturbance caused by diabetes\textsuperscript{25}, episodes of hypoglycaemia and service usage were analysed using the Mann-Whitney $U$-test; most recent
reported HbA1c values were analysed using Student’s $t$-test. Categorical data on self-reported hypoglycaemia, ophthalmic and urine checks, service usage and estimation of proportions of patients likely to transition to adult services requiring CSII initiation and/or support were analysed using the Chi-square or Fisher’s Exact test. Analyses pertaining to ophthalmic and urine checks were undertaken on data from all respondents, then, in light of complication screening recommendations for young people, solely for those with greater than five years type 1 diabetes duration$^{27}$. Multiple regression analyses were used to identify predictors of young people’s attitudes, perceptions and experiences with diabetes management, with dependent variables of the summary scores for the PDSMS, perceived diabetes-related knowledge, independence in changing insulin doses, independence in care of diabetes overall, disturbance caused by diabetes and most recent reported HbA1c values. In light of the well-known associations between attitudes, beliefs and behaviours$^{28}$, each was also examined as potentially predictive variables. Other potentially predictive variables were selected based upon clinical insights and prior studies: current CSII use (Yes/No), sex, age, diabetes duration and metropolitan versus non-metropolitan residence$^{7, 29, 30}$. Data were entered into each model using the backwards method, with missing data deleted listwise. A $p$ value of $< .1$ was applied for exclusion from the model and $< .05$ was taken to indicate significance.

RESULTS:
Of the 295 questionnaires distributed 107 (36.3%) were returned partially or fully completed; response rate was difficult to determine as the recorded address may not have been current and not all potential participants may have received the survey. Where reported, 49 questionnaires were completed by a young person alone, four by parents alone and 53 by a young person and parent together. The young people were mean age 15.1 years. The sexes were approximately equally represented with 57.9% male; 5.6% self-identified as Aboriginal and/or Torres Strait Islander. Respondents reported mean age at type 1 diabetes diagnosis and diabetes duration of 9.3 and 5.9 years, respectively. Almost one third (30.8%) resided in metropolitan areas; almost all (91.6%) were full-time students and lived with family members (95.3%) (Table 1). CSII was the current method of insulin delivery for 42 (39.3%) respondents, with a further eight having used this in the past (n = 50, 46.7%); mean (SD) age at commencement was 12.4 (2.6) years. Where reported, current CSII users and non-users differed in that current users were significantly younger at diagnosis, with significantly longer diabetes duration (Table 1).

Attitudes and perceptions

Respondents’ (n = 86) attitudes towards and perceptions of their diabetes management self-efficacy were largely positive. They mostly agreed that they handled themselves well with regards to their diabetes; were able to manage things related to their diabetes as well as most others; that they succeeded in the things they did to manage their diabetes; and were able to achieve management plans (Table 2). Mostly, they did not find it difficult to find effective solutions for management problems; efforts to change things about their diabetes worked;
typical plans for diabetes management worked out well; and management turned out as planned. Reported attitudes and perceptions were not statistically significantly different between current CSII users and non-users for individual items or the measure summaries (Table 2). Respondents were significantly more likely to report greater self-efficacy for diabetes self-management (have a higher PDSMS summary score) if they were younger, reported greater independence in their diabetes care, were less disturbed by their diabetes diagnosis, and reported lower most recent HbA1c values (Table 3).

Overall, 87 respondent perceived their diabetes-related knowledge as moderate (median (25, 75 quartile) score 75 (63, 76) of 100). Respondents reported changing their insulin dosages independently some of the time (scoring 69 (21, 94) of 100) and that they were somewhat independent in overall diabetes management (scoring 76 (62, 98) of 100). Again, there were no statistically significant differences in responses of current CSII users (n = 36) and non-users (n = 51) for these three items. Respondents were more likely to report independence in changing insulin dosages if they reported greater management self-efficacy (a higher PDSMS score), greater independence in their diabetes care overall, and had a higher most recent HbA1c (Table 3). They were more likely to report independence in their diabetes care overall if they were older, reported greater management self-efficacy (a higher PDSMS score), greater diabetes-related knowledge and independence changing insulin dosages (Table 3).

Experiences
Respondents’ (n = 86) indicated they were disturbed by their diabetes for about half the time (median (25, 75 quartile) score of 50 (25, 75)), with no significant difference between CSII users and non-users. Respondents were more likely to report disturbance by their diabetes if they resided in non-metropolitan locations, perceived less self-efficacy to self-manage their diabetes (a lower PDSMS score), and reported greater diabetes-related knowledge (Table 3). Patterns of associations between knowledge, attitudes and experiences of diabetes modelled by regression analysis are illustrated in Figure 1.

Recent HbA1c values were supplied by 65 (60.7%) respondents; mean (SD, min, max) values were 8.0% (1.6%, 5.2%, 12.9%) (Table 1). Recent values were considered (n = 80) higher than usual by 25 (31.3%), usual for 33 (41.3%) and lower than usual by 10 (12.5%). Whilst there was no statistically significant difference between values reported by current CSII users and non-users (n = 28, mean (SD, min, max) 8.3% (1.4, 6.3, 11.2) versus n = 37, 7.8% (1.7, 5.2, 12.9); t = 1.454, P = .151 (95% CI = -.21, 1.36)), a mean difference of 0.5% might be considered clinically significant. Values were non-significantly higher in respondents who resided in a non-metropolitan location (n = 39, 8.2% (1.7, 6.0, 12.9) versus n = 26, 7.7% (1.4, 5.2, 10.8); t = -1.279, P = .206 (95% CI = -1.31, .29)).

In the previous month hypoglycaemia was reported by 73 (77.7%) of 94 respondents, who reported experiencing a median (25, 75 quartile) 3 (1, 5) hypoglycaemic episodes per week. There was no statistically significant difference in responses from current CSII users compared to non-users for both any occurrence (yes/no) (n = 28 (75.7) versus n = 45
(78.9%); \( X^2 = 0.138, P = .71 \) and frequency (2.5 (1.25, 4) versus 3 (1, 5) events). Of 87 respondents, 33 (37.9%) reported having a hypoglycaemic episode that required assistance since their diabetes diagnosis; not statistically significant, these severe episodes were reported by a greater proportion of non-CSII users than CSII users (n = 23, 45.1% versus n = 10, 27.8%). The method of insulin delivery utilised during these episodes was, however, unknown.

When asked about diabetes complications screening within routine care in the previous year, 58 of 87 respondents (66.7%) reported having an ophthalmic examination for retinal disease and 66 (75.9%) reported urine checks for renal disease. Distribution was similar for CSII users and non-users: ophthalmic examinations (n = 25 (69.4%) versus n = 33 (64.7%); \( X^2 = .213, P = .644 \); urine checks (n = 27 (75%) versus n = 39 (76.5%); \( X^2 = .025, P = .875 \). Of respondents with greater than five years diabetes duration (n = 46), 34 (73.9%) reported having an ophthalmic examination and 37 (80.4%) reported having a check for renal disease. However distribution was not always similar for CSII users and non-users: for ophthalmic examinations (n = 19 (73.1%) versus n = 15 (75%); \( X^2 = .022, P = .883 \) and urine checks (n = 18 (69.2%) versus 19 (95%); Fisher’s exact = No value, \( P = .057 \), respectively.

Diabetes-related care was commonly accessed through acute services. Within the previous year, 11 of 92 respondents (12%) reported a diabetes-related ED presentation, and 27 of 96 respondents (28.1%) reported a diabetes-related hospital admission (excluding an admission for T1D diagnosis); overall, 33 respondents (30.83%) had used acute services for diabetes-
related problems (excluding for T1D diagnosis). Again there was no statistically significant difference in responses of CSII users compared to non-users (Table 4).

Future preferences

Substantial numbers (n = 39, 41.1%) of the 95 respondents who indicated their future preferences for insulin delivery method intended to use CSII as an adult; this included 31 of 42 (73.8%) current CSII users and 8 (15.1%) of 53 (of 65) respondents not presently using this technology. Although not statistically significant, a greater proportion of those intending to use CSII lived in non-metropolitan settings (n = 25 (64.1%) versus n = 14 (35.9%)). Additionally, 41 respondents either had not thought about it or could not anticipate their future plans, with 10 (23.8%) current CSII users planning to discontinue this method of insulin delivery.

DISCUSSION:

The majority of children and adolescents with T1D had positive attitudes and perceptions of their self-efficacy and diabetes management, but were moderately disturbed by their diabetes and experienced sub-optimal management outcomes. Overall there was no statistically significant difference in responses from CSII users and non-users. A large proportion of respondents indicated that they intended to use this therapy when accessing adult diabetes services; information of value for health service planning.
Findings indicate the inter-related roles of perceived self-efficacy, diabetes-related knowledge, independence in diabetes management and sense of disturbance caused by diabetes (Figure 1). However the influence of age appeared complex. Perhaps younger respondents perceived they had better diabetes self-efficacy and knowledge because they were shielded by their parents’ contribution to their management; consistent with increasing independence in diabetes care overall with increasing age. With greater diabetes knowledge linked with greater sense of disturbance by their diabetes, education needs to be tailored to achieve better self-management, as it may otherwise function to cause anxiety or distress and may result in worse outcomes. The suggestion of greater disturbance in non-metropolitan residents was perhaps linked to the greater isolation and lack of peer support experienced in rural areas and warrants further exploration.

Overall, the patterns of glycaemic control reported by these participants could not be described as optimal. Findings were consistent with previous studies of young adults with T1D in this region of NSW and elsewhere, and are cause for concern, especially considering the accompanying positive attitudes, high perceived self-efficacy and diabetes self-management abilities also reported. High rates of hypoglycaemia and acute service usage for diabetes-related problems were also consistent with findings from young adults with T1D. CSII use did not appear to confer a significant advantage in glycaemic control, although this study lacked statistical power to demonstrate this. However findings highlight the importance of good preparation and support for CSII use.
There is broad consensus that a prospective CSII user should be assessed by a multidisciplinary team in relation to multiple criteria to ensure appropriate targeting of this technology\textsuperscript{16, 40}. In this study it is unclear whether and how this, and re-evaluation post commencement, occurred. Respondents’ CSII use (39.3\%) was broadly consistent with national data, supporting the generalisability of findings in this young population; one third of people with type 1 diabetes aged under 20 years across Australia are reported to use CSII technology\textsuperscript{16}. Eight current non-users had used CSII in the past. Varied rates of discontinuance have been reported, and although up to 18\% of children and young people have been reported to discontinue CSII within the first few years of use\textsuperscript{10, 29}, lower rates have also been reported\textsuperscript{41, 42}. Given the cost to provide CSII and the human resources required to support CSII users, discontinuance and any failure to improve real life clinical outcomes are disappointing\textsuperscript{43}. One reason for sub-optimal outcomes might be that stretched diabetes teams, especially in rural areas, lack adequate specialist resources to provide the more complex and time consuming support needed to optimise results\textsuperscript{35, 44}. Where this is the case, service redesign is required to improve support particularly but not exclusively for CSII users. Other technologies such as video-conferencing may also be of benefit\textsuperscript{45}, and should be explored.

Limitations of the study include the use of self-report data, and sampling from only one regional health service. The sample size was relatively small and the survey entailed only brief assessments of perceived disease knowledge, self-care independence and sense of disturbance caused by diabetes. No data were available on participants’ and their parents'/guardians’ economic status, and we were therefore not able to consider whether
financial concerns such as lack of access to private insurance or loss of the Australian Government subsidy for a CSII device at age 18 years may have, for example, influenced access or intention to use CSII\textsuperscript{21}. The survey was completed, variously, by the young person, their parents, or both; findings therefore contain a mix of the young person’s independent views and what the parents think their views are. We set out to obtain the views of young people, and accepted that some parental input might be needed to obtain this, even to the extent of a parent responding as proxy. The strengths of the study derive from successfully recruiting a ‘hard to access’ group across a wide and diverse geographical and sociological area, the majority of whom completed the survey unaided. Incremental changes in technology since the study was undertaken are unlikely to yield different findings.

In summary, opportunities for enhanced diabetes service support were identified, with CSII in particular not currently appearing to achieve its full potential. Service structure needs to keep pace with the changes in technology and its rapid uptake by young people. Policy-makers and managers should align service delivery to patient goals and preferences to maximise service as well as patient benefit. This must include regular access to multidisciplinary team support with specialist medical input, which is particularly lacking for CSII users and those outside metropolitan areas.
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AUTHOR’S CONTRIBUTIONS:

Study proposal developed by LP, JL, JD and KS. Data collected by JD.

Analyses conducted by SJ and LP. Paper drafted, revised and agreed by all authors.

All authors read and approved the final manuscript.
REFERENCES


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Table 1: Demographic details and reported glycaemic control

<table>
<thead>
<tr>
<th>Variable</th>
<th>Overall [n107 unless stated]</th>
<th>Current CSII user [n42 unless stated]</th>
<th>Non-CSII user [n65 unless stated]</th>
<th>Test value</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-time student (n%)</td>
<td>98 (91.6)</td>
<td>39 (92.9)</td>
<td>59 (90.8)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Lives with family members (n%)</td>
<td>102 (95.3)</td>
<td>40 (95.2)</td>
<td>62 (95.4)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Male gender (n%)</td>
<td>62 (57.9)</td>
<td>24 (57.1)</td>
<td>38 (58.5)</td>
<td>$X^2 = .018$</td>
<td>.893</td>
</tr>
<tr>
<td>Age, mean (SD, min-max) yrs</td>
<td>15.1 (2.0, 10.6 - 18.8)</td>
<td>15.4 (1.9, 12.3 - 18.4)</td>
<td>14.9 (2.1, 10.6 - 18.8)</td>
<td>$U = 1108.5$</td>
<td>.102</td>
</tr>
<tr>
<td>Age at diagnosis, mean (SD, min-max) yrs</td>
<td>n104</td>
<td>n41</td>
<td>n63</td>
<td>$U = 964$</td>
<td>.029</td>
</tr>
<tr>
<td></td>
<td>9.3 (3.7, 0.9 - 16.8)</td>
<td>8.4 (3.1, 1.5 - 14.5)</td>
<td>9.8 (4.0, 0.9 - 16.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes duration, mean (SD, min-max) yrs</td>
<td>n104</td>
<td>n41</td>
<td>n63</td>
<td>$U = 796$</td>
<td>.001</td>
</tr>
<tr>
<td></td>
<td>5.9 (3.5, 0.2 - 13.7)</td>
<td>7.1 (2.7, 1.7 - 13.7)</td>
<td>5.1 (3.7, 0.2 - 12.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metropolitan residence† (n%)</td>
<td>33 (30.8)</td>
<td>16 (38.1)</td>
<td>17 (26.2)</td>
<td>$X^2 = 1.706$</td>
<td>.192</td>
</tr>
<tr>
<td>Most recent HbA1c (%), mean (SD, min-max)</td>
<td>n65</td>
<td>n28</td>
<td>n37</td>
<td>$t = 1.454$</td>
<td>.151</td>
</tr>
<tr>
<td></td>
<td>8.0 (1.6, 5.2 - 12.9)</td>
<td>8.3 (1.4, 6.3 - 11.2)</td>
<td>7.8 (1.7, 5.2 - 12.9)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

† Metropolitan versus non-metropolitan according to Australian Standard Geographical Classification. CSII = Continuous Subcutaneous Insulin Infusion. Yrs = Years. $X^2$ = Chi-square test. $U$ = Mann-Whitney $U$-test. $t$ = Student’s $t$-test.
Table 2: Attitudes and perceptions (Perceived Diabetes Self-Management Scale-PDSMS)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Overall</th>
<th>Current CSII user</th>
<th>Non-CSII user</th>
<th>Mann-Whitney U test value</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Succeed in things to manage</td>
<td>4 (3, 4)</td>
<td>4 (3, 4)</td>
<td>4 (4, 5)</td>
<td>715</td>
<td>.076</td>
</tr>
<tr>
<td>Able to achieve plans</td>
<td>n85, 4 (3, 4)</td>
<td>n35, 4 (3, 4)</td>
<td>4 (4, 5)</td>
<td>747.5</td>
<td>.218</td>
</tr>
<tr>
<td>Manage as well as others</td>
<td>4 (4, 5)</td>
<td>4 (4, 5)</td>
<td>4 (4, 5)</td>
<td>813.5</td>
<td>.395</td>
</tr>
<tr>
<td>Handle diabetes well</td>
<td>4 (4, 5)</td>
<td>4 (4, 4.75)</td>
<td>4 (4, 5)</td>
<td>846</td>
<td>.607</td>
</tr>
<tr>
<td>Effective solutions†</td>
<td>4 (3, 4)</td>
<td>4 (3, 4)</td>
<td>4 (3, 4)</td>
<td>869</td>
<td>.777</td>
</tr>
<tr>
<td>Doesn’t turn out way liked†</td>
<td>4 (3, 5)</td>
<td>4 (3, 5)</td>
<td>4 (3, 4.25)</td>
<td>887</td>
<td>.906</td>
</tr>
<tr>
<td>Efforts to change don’t work†</td>
<td>n85, 4 (3, 4)</td>
<td>n35, 4 (3, 4)</td>
<td>4 (3, 4)</td>
<td>863.5</td>
<td>.914</td>
</tr>
<tr>
<td>Plans don’t work out well†</td>
<td>4 (3, 4)</td>
<td>4 (3, 4)</td>
<td>4 (3, 4)</td>
<td>899</td>
<td>.993</td>
</tr>
<tr>
<td>Summary score</td>
<td>n84, 31 (26, 34)</td>
<td>n34, 31 (26, 34)</td>
<td>31 (26.75, 36)</td>
<td>782.5</td>
<td>.537</td>
</tr>
</tbody>
</table>

†Reverse scored. 1 = Strongly disagree, 5 = Strongly agree. CSII = Continuous Subcutaneous Insulin Infusion.
Table 3: Multiple regression (backwards entry)

<table>
<thead>
<tr>
<th>Dependent</th>
<th>Independent in care of diabetes†</th>
<th>PDSMS†</th>
<th>Disturbed by diabetes†</th>
<th>Independence changing insulin dosages†</th>
<th>Most recent HbA1c</th>
<th>Knowledge of diabetes†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independent</td>
<td>Beta (P value)</td>
<td>Beta (P value)</td>
<td>Beta (P value)</td>
<td>Beta (P value)</td>
<td>Beta (P value)</td>
<td>Beta (P value)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age overall</td>
<td>.490 (&lt; .001)</td>
<td>-.324 (.003)</td>
<td></td>
<td></td>
<td>-.237 (.04)</td>
<td>-.341 (.019)</td>
</tr>
<tr>
<td>Metropolitan residence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes/No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PDSMS†</td>
<td>.255 (.007)</td>
<td>-</td>
<td>-.688 (&lt; .001)</td>
<td>.255 (.044)</td>
<td>-.632 (&lt; .001)</td>
<td></td>
</tr>
<tr>
<td>Knowledge of diabetes†</td>
<td>.227 (.015)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independence changing</td>
<td>.288 (.004)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.345 (.005)</td>
</tr>
<tr>
<td></td>
<td>Model 1</td>
<td>Model 2</td>
<td>Model 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------------</td>
<td>-----------</td>
<td>-----------</td>
<td>-----------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independence in care of diabetes†</td>
<td>0.378 (.001)</td>
<td>0.535 (&lt; .001)</td>
<td>0.572 (&lt; .001)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disturbed by diabetes†</td>
<td>-0.428 (&lt; .001)</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Most recent HbA1c</td>
<td>-0.302 (.003)</td>
<td>0.356 (.004)</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Model number, R²</td>
<td>7, 0.626</td>
<td>7, 0.589</td>
<td>7, 0.495</td>
<td>7, 0.464</td>
<td>8, 0.382</td>
<td>9, 0.226</td>
</tr>
</tbody>
</table>

† = Summary score. n=59. CSII = Continuous Subcutaneous Insulin Infusion. PDSMS = Perceived Diabetes Self-Management Scale. The independent variables Current CSII use Yes/No and Diabetes duration overall were removed from all models.
### Table 4: Service usage

<table>
<thead>
<tr>
<th>Variable</th>
<th>Overall</th>
<th>Current CSII user</th>
<th>Non-CSII user</th>
<th>Test value</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%) unless</td>
<td>n (%) unless</td>
<td>n (%) unless</td>
<td>FET = not</td>
<td>.741</td>
</tr>
<tr>
<td>Variable</td>
<td>stated</td>
<td>stated</td>
<td>stated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any DR ED presentation</td>
<td>n92</td>
<td>n34</td>
<td>n58</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>11 (12)</td>
<td>3 (8.8)</td>
<td>8 (13.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DR ED presentations, median (25, 75)</td>
<td>n11</td>
<td>n3</td>
<td>n8</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 (1, 4)</td>
<td>2 (2,-)</td>
<td>1.5 (1, 4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any DR hospital admission†</td>
<td>n96</td>
<td>n39</td>
<td>n57</td>
<td>X² = &lt; .001</td>
<td>.988</td>
</tr>
<tr>
<td>Yes</td>
<td>27 (28.1)</td>
<td>11 (28.2)</td>
<td>16 (28.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DR hospital admissions†, median (25, 75)</td>
<td>n27</td>
<td>n11</td>
<td>n16</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 (1, 1)</td>
<td>1 (1, 1)</td>
<td>1 (1, 1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any DR acute service usage†</td>
<td>n100</td>
<td>n40</td>
<td>n60</td>
<td>X² = .008</td>
<td>.931</td>
</tr>
<tr>
<td>Yes</td>
<td>33 (33)</td>
<td>13 (32.5)</td>
<td>20 (33.3)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**DR acute service usage†, median (25, 75)‡**  

<table>
<thead>
<tr>
<th></th>
<th>n20</th>
<th>n5</th>
<th>n15</th>
<th>U</th>
<th>.612</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 (1, 3.75)</td>
<td>1 (1, 2.5)</td>
<td>1 (1, 4)</td>
<td></td>
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</tr>
</tbody>
</table>

†Excluding admissions for type 1 diabetes diagnosis.
‡Data excluded from analysis where not present for both ED and hospital admissions.
CSII = Continuous Subcutaneous Insulin Infusion.  DR = Diabetes-related.
ED = Emergency Department.  $X^2$ = Chi-square test.  FET = Fisher’s Exact Test.  $U$ = Mann-Whitney $U$-test.
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Author/s:
Perry, L; James, S; Steinbeck, K; Dunbabin, J; Lowe, J

Title:
Young people with type 1 diabetes mellitus: Attitudes, perceptions, and experiences of diabetes management and continuous subcutaneous insulin infusion therapy.

Date:
2017-06

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