

The development of an information booklet for students with type 1 diabetes

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Article points

1. A literature search confirmed the lack of educational material for university students with type 1 diabetes.
2. The authors designed an information booklet using advice from DSNs, students with diabetes, existing patient information leaflets and textbooks.
3. The booklet was piloted to individuals attending young persons' diabetes clinics using questionnaires to evaluate the contents, resulting in positive feedback.

Key words

- Alcohol
- Education
- Type 1 diabetes
- University students

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The self-management of diabetes at university is challenging for young people. Research has shown that an unstructured lifestyle and risky behaviours, such as alcohol consumption, mean that optimal blood glucose control is often difficult to achieve. There is currently a lack of educational material providing realistic advice on university life. In this study, the authors aimed to design and pilot a booklet in order to highlight the issues relevant to young people with diabetes, which are currently not addressed in patient educational material.

Starting university, with its typically unstructured and chaotic lifestyle, is a potentially challenging time for type 1 diabetes management. Research has shown that university students are more likely to involve themselves in risky behaviours, such as taking drugs and alcohol, with negative effects on diabetes control (Plant and Plant, 1992). It is the role of all diabetes health professionals to adapt diabetes management to the lifestyles of their patients. The lifestyle of a student has been described as a “grey area” in diabetes services (Cheyette, 2006).

Attendance at young persons' diabetic clinics and discussions with young person diabetes teams revealed a lack of realistic information for people with type 1 diabetes starting university. In an effort to resolve this problem, the authors of this article have developed a diabetes booklet entitled “Starting Uni with Diabetes”.

Research methodology

Literature search

The authors conducted a literature search to identify the current information available for university students with diabetes, using the following search terms: “diabetic education”; “patient education”; “educational material”; “patient leaflet”; and combined “student”, “adolescent” and “diabetes”. Their search identified several patient education leaflets concerning adolescent diabetes control. However, there was a paucity of information regarding diabetes management at university.

Designing the booklet

The booklet content was derived from textbook examples from existing patient information leaflets (Barlow and Bishop, 1996; Secker, 1997; Hanas, 2004; Diabetes UK, 2012b), advice from DSNs at the Royal United Hospital, Bath,

and suggestions from a sample of university students with type 1 diabetes. The end-result was a booklet containing the following nine sections: “alcohol”; “how do I tell people about my diabetes?”; “sports”; “stress”; “drugs”; “healthy eating”; “sex”; “insulin”; and “sick days”.

The authors used desktop publishing to produce the booklet (Diabetes UK, 2012a; see *Figures 1, 2 and 3*). Coloured text and bright images aimed to be eye-catching and text was displayed in bullet points or short paragraphs to convey the key points. As the authors considered that the readers would respond more positively to advice from other young people with diabetes, 10 quotes from students were used to communicate pertinent points. The authors aimed to use simple, non-judgemental language and, rather than presenting a list of “dos and don’ts”, endeavoured to give realistic advice, allowing readers to make their own, well-informed decisions.

Evaluating the booklet

An evaluation questionnaire was used to assess the booklet (Streiner and Norman, 1998), consisting of 14 questions regarding personal information to provide characteristics of respondents, including age, sex, university or educational institute, and questions about diabetes management, including the frequency of hypoglycaemic episodes, HbA_{1c}, perceived glycaemic control (defined as self-assessment of diabetes control ranked on a five-point scale [1=excellent; 2=good; 3=fair; 4=poor; 5=terrible]), history of diabetic ketoacidosis (DKA) and history of hypoglycaemia requiring assistance from others. Seven questions asked for feedback on the booklet. Three of the questions required numerical responses, ranging from 1 to 5 (1=very; 2=quite; 3=fairly; 4=not really; 5=not at all), constituting the quantitative aspect of the study. Four of the questions required free-text responses.

The evaluation questionnaire and booklet were distributed to young people waiting for their appointments at secondary care clinics. Recipients were selected on the basis of the following inclusion criteria: diagnosis of type 1 diabetes, aged 16–25 years and willingness to participate. Young persons’ diabetes clinics at the following locations were visited: the John Radcliffe

Hospital, Oxford; the Royal United Hospital, Bath; Southmead Hospital, Bristol; the Great Western Hospital, Swindon; and Bristol University Students’ Health.

Analysis of the evaluation questionnaire

For numerical responses, the authors performed univariate analysis with multiple regression analysis to correct for the following possible confounding factors: sex; age; ethnicity; HbA_{1c}; frequency of hypoglycaemic episodes; university or college course (arts or sciences); history of a serious hypoglycaemic episode (defined as “requiring assistance from others”); history of DKA; perceived diabetes control; and frequency of blood glucose measurements per day. Qualitative analysis of the answers to the four questions eliciting free-text responses was used to identify areas for booklet improvement.

Findings

No other patient information resources addressing type 1 diabetes management at university were identified by the literature search or through discussions with young people with diabetes. Evaluation questionnaires were completed by 52 students (mean age 19.2 years; 23 male, 25 female; and four students for whom the gender

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Figure 1. Cover page for the booklet.

Page points

1. In order to obtain feedback on the booklet, evaluation questionnaires were completed by 52 university students.
2. The mean score for “usefulness” of the booklet was 1.9 (1=“very”; 5=“not at all”) and 49% of responders considered the “alcohol” section most helpful.
3. Participants would have liked more information on the effects of illicit drugs on the blood glucose and insulin pumps.



Figure 2. Sample page from the booklet, with advice regarding alcohol consumption and a quote from a student with type 1 diabetes.

was not recorded). Of all the respondents, 25 were enrolled on university courses, one was at college, three were applying for university and 23 chose not to disclose their educational status. Their characteristics are summarised in *Table 1*. All three numerical feedback questions, that is the “usefulness of information”, “sufficiency of information” and “usefulness of information if received in university starting pack”, received a mean score of 1.9 (scoring range: 1=very; 5=not at all). The mean score for “sufficiency of information” was 2.13 for males and 1.64 for females ($P=0.03$). There was no significant gender difference in “usefulness of information”, for which the mean score in females was 1.88 compared with 1.91 in males ($P=0.90$). None of the independent variables predicted “usefulness” or “usefulness if received in university starting pack”. However, gender was a significant predictor of “sufficiency of information”, as the females found it less “sufficient” ($P=0.005$). Responses to free-text questions are summarised in *Table 2*.

The “alcohol” section was identified as “particularly helpful” by nearly half the participants (49%) and valued in teaching “something not known before” by 16%.

Responders specifically commented on the helpfulness of the information relating to “having breakfast after alcohol” and “alcohol and taking insulin”.

The “drugs” section was highlighted as an area requiring more information by 13% of the participants. For example, one participant said:

“Pretending that drugs like cannabis don't happen at university is naïve... I think it would be really useful to have more detail on... what the effects are on your blood sugar.”

Eighteen per cent of participants claimed that they had learnt something new from the “stress” section, particularly that stress increases blood glucose levels. Four female participants identified “stress” as a section requiring further information. This corresponds with the findings from the regression analysis in that, overall, the female participants found the booklet information less “sufficient” than the male participants.

The section “how do I tell people about my diabetes?” was assessed as particularly helpful by 15% of the responders, while 5% conversely found it unhelpful.



Figure 3. Sample page from the booklet, with advice regarding blood glucose monitoring and alcohol consumption.

Table 1. Characteristics of participants in pilot study.

Age (years)	HbA _{1c} (%)	Self-assessment of type 1 diabetes control (1–5)*	Self-measurement of blood glucose per day	Episodes of hypoglycaemia per week	Self-reported history of serious hypoglycaemia †
19.2±2.1	8.7±1.7	2.5±0.7	3.1±2.1	2.6±2.9	48.1%

Data are given as mean ± standard deviation
 *Score range for diabetes self-assessment (1=excellent; 2=good; 3=fair; 4=poor; 5=terrible).
 †Defined as hypoglycaemic episode “requiring assistance from others”.

Table 2. Highest frequency responses to the four questions eliciting free-text responses.

Section of booklet identified as “particularly helpful” (% n=41)	Section of booklet requiring “more information” (% n=32)	Section of booklet identified as “unhelpful” (% n=35)	Section of booklet identified as teaching something “not known before” (% n=27)
Alcohol (49)	No section (50)	No section (71)	No section (29)
“How do I tell people about my diabetes?” (15)	Drugs (13)	“How do I tell people about my diabetes?”(2)	Stress (18)
Sick days (13)	Stress (11)	Drugs (2)	Alcohol (16)
All sections (13)	Sports (11)	Sex (2)	Drugs (3)

One participant said:

“... made a big deal out of telling others about your diabetes.”

Other responses of note include:

“Tips from students were personal advice and not forceful.”

“Very useful to have a guide with all advice in. The last thing you want to do when ill with diabetes is to search through loads of flyers to try and find the relevant one.”

“Would have been helpful when I was in first year, not so much now I’m in second year.”

“Would have been useful for friends to have read this.”

Qualitative analysis of the feedback highlighted a number of useful topics that were not included in the booklet, such as travelling and benefits advice (see *Box 1*).

Discussion

The first version of the patient information booklet for university students with type 1 diabetes generated positive feedback (see *Box 1* for the key findings). The analysis of the feedback suggested that the contents of the booklet had

a broadly equal appeal across all participants in the study. Gender differences in perceived “sufficiency” of the booklet information were observed with females reporting insufficient information, particularly on the impact of stress on diabetes. The qualitative component of the analysis highlighted several important issues that were not included in the first version of the booklet.

Students found the “alcohol” section useful, which contained details about realistic ways to avoid complications of diabetes and drinking, such as avoiding drinks with a high sugar content and leaving their university door unlocked so that someone could check on them in the morning. The sections that were identified as teaching

Box 1. Key points from the feedback on the information booklet.

- The students considered the “alcohol” section most useful.
- Participants would have liked more information on the effects of illicit drugs on blood glucose levels and the females, in particular, wanted to know about how stress influences diabetes control.
- Advice on travelling, benefits, insulin pumps, managing prescriptions, useful university contacts and the difference between long- and short-term carbohydrates were identified as important topics that were not included in the booklet.

“The findings have highlighted the key issues that DSNs working with young people should be aware of, such as drugs and alcohol, which do not seem to be covered by the current resources in a sufficiently non-judgemental way.”

something new to the participants were that of “drugs”, “sports” and “alcohol”. There were, however, some difference in opinion. The “how do I tell people about my diabetes?” was highlighted by individual students as both particularly helpful and unhelpful. Written responses suggested that too much emphasis was placed on one approach to informing others about their condition, rather than offering a range of options. One participant would have liked more information on how different illegal drugs affect blood glucose levels. This presents a difficult balance between allowing adolescents to make informed decisions and ensuring that drugs are not promoted. The relatively small number of students participating in the study is a limitation that should be considered. Selection bias is possible as clinic non-attenders were not included, favouring feedback from people already engaged with secondary care. One of the authors distributed the leaflets and questionnaires, creating another potential source of bias. Though participants may have felt obliged to give more positive feedback, the authors aimed to reduce this by asking participants to be “as honest as possible”.

Conclusion

Educational interventions in diabetes have proved to be beneficial in young people. Well-informed individuals take a more active role in diabetes self-management, with more frequent blood glucose measurements, improved blood glucose control and fewer experiences of hypoglycaemic episodes or DKA (Hampson et al, 2001; Thakurdesai et al, 2004; Peyrot et al, 2009). Longer-term goals include improving body weight, blood pressure, HbA_{1c} and cholesterol, with a view to reducing diabetes complications (Mühlhauser and Berger, 2000; Heisler et al, 2002; Ellis et al, 2004).

As confirmed by the literature search, there is no specific diabetes education material available for young people with diabetes starting university (Funnell et al, 2011). This study has provided the evidence needed to justify the production of a readily available, realistic information booklet for this target group. The findings have highlighted the key issues that DSNs working with young people should be aware of, such as drugs and alcohol,

which do not seem to be covered by the current resources in a sufficiently non-judgemental way. Based on the feedback, the authors plan to modify the booklet, with the ultimate aim of making it available to all university students with type 1 diabetes. Although this pilot study focused on students, it is not unreasonable to suggest that all adolescents with diabetes need more realistic advice on the key issues. ■

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The “Starting Uni with Diabetes” pilot booklet is available online via Diabetes UK at: <http://bit.ly/RoM6UD>