What do children, young people and parents want from a diabetes dietitian? A user survey

Laura Bull

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Article points

1. The diabetes dietetic service should be patient-led and meet the needs of young people and parents.
2. Parents prefer contact with the diabetes dietitian at multidisciplinary team clinics and via websites, email and telephone.
3. Parents would like dietetic support in managing exercise, tricky meals and carbohydrate counting.
4. Parents and young people's needs vary; therefore, the dietetic service should be diverse and flexible.

Key words

- Diabetes dietitian
- Service delivery
- Survey

Author

Laura Bull is Senior Specialist Dietitian, Children and Young People's Diabetes Service, University College London Hospitals.

The Best Practice Tariff requires annual dietetic review alongside regular multidisciplinary team clinics. In this study, an electronic survey was performed to assess what service users wanted from their dietitians. The survey was sent to 403 families and 100 completed surveys were returned. Key themes identified were support with managing exercise; tricky meals (understanding glycaemic index, using different pump bolus options and managing pizzas and takeaways); and support with carbohydrate counting (eating out and using apps and websites). The dietitian's role in promoting healthy eating and supporting young people to gain independence with carbohydrate counting was also highlighted as important. Parents preferred contact with the dietitian at multidisciplinary clinics and via email, websites and telephone, rather than a separate annual dietetic review appointment. The results of this survey provide valuable information for the development of diabetes dietetic services in the future and highlight important areas of knowledge and skills for paediatric dietitians delivering diabetes care and education.

The prevalence of type 1 diabetes in children and young people (CYP) is increasing. There are at least 31 500 people under the age of 19 years in the UK with diabetes, about 95% of whom have type 1 diabetes (Diabetes UK, 2016). Only 26.6% of CYP with type 1 diabetes achieve the recommended HbA_{1c} target of <58 mmol/mol (7.5%; Royal College of Paediatrics and Child Health, 2017). Furthermore, the latest NICE guideline now recommends a target HbA_{1c} of <48 mmol/mol (6.5%; NICE, 2015).

Nutritional management is one of the cornerstones of diabetes care and education, and a specialist paediatric dietitian with experience in childhood diabetes should be part of the multidisciplinary team (MDT) caring for CYP with diabetes (Smart et al, 2014). Dietetic time allocated for CYP's diabetes services increased following the introduction of the Best Practice Tariff (BPT; Department of Health, 2013). New posts were created or time was increased for existing posts to meet the criteria that all CYP should be reviewed quarterly by a dietitian as part of the MDT clinic, and that all CYP should be offered at least one additional dietetic review annually.

The CYP's diabetes service at University College London Hospitals (UCLH) is a large tertiary service. CYP attend the service from across the UK, and approximately 75% utilise insulin pump therapy, with the remainder on multiple daily injection therapy. The aim of this survey was to find out what parents and CYP would like from their dietitian and how they would like to interact; to assess whether the current service was meeting these needs; and to assist in planning future service development. No surveys of this kind had been carried out before.

Box 1. Survey design.

Question 1. Are you a young person with diabetes or a parent of a child with diabetes?

Questions 2–6. These are ways the dietitian has helped other people. Which ones interest you? (tick all that apply) *[see Table 1 for the list of suggested topics]*

Question 7. Do you prefer to meet the dietitian on the same day as your consultant appointment or book a separate dietitian appointment?

Question 8. I can support you in the following ways. Which ones interest you? (tick all that apply) *[see Table 2 for the list of methods of support]*

Question 9. Would you be interested in doing any of the following activities while waiting for your appointment? (tick all that apply) *[see Table 3 for the list of suggested topics]*

Question 10. Would you find group sessions with the dietitian in any of the following areas useful? (tick all that apply) *[see Table 4 for the list of suggested topics]*

Method

Survey design

The survey was created using SurveyMonkey®, an online questionnaire-designing tool, and for this reason was limited to 10 questions and a maximum of 100 respondents. The draft survey was reviewed by the MDT and parent representatives to ensure the questions were at an appropriate level for the target audience. *Box 1* shows the final questionnaire used. All questions offered multiple-choice answers, with no limitation on the number of options that could be chosen, as well as the opportunity to add free text. Given the novel nature of this survey, it has not been validated.

Data collection

The survey was distributed to every patient within the service at the time of the survey (n=403). An online link to the questionnaire was sent to all patients with their annual dietetic review invitation letter. Parents and CYP were also given the opportunity to complete the questionnaire on hand-held electronic devices within the clinic waiting room. The link to the online questionnaire was also distributed electronically via the Families with Diabetes National Network mailing list.

Table 1. Dietetic topics ranked in order of interest to survey respondents.

Topic	Interest (% of total respondents)
Exercise – stopping hypos or high levels	63
Dealing with tricky situations – advanced boluses	46
Carbs in restaurant foods and eating out	44
Getting a better HbA_{1c}	43
Dealing with tricky situations – understanding glycaemic index	42
Dealing with tricky situations – pizzas and takeaways	41
Dealing with tricky situations – insulin timing around meal times	40
Special diets – healthy eating	35
Which apps, books and websites are useful	34
Ways to help make carbohydrate counting quicker and easier	33
Carbs in homemade recipes	27
Dealing with tricky situations – alcohol	19
Exercise – build up muscle	17
Getting ready for secondary school	17
Carbohydrate counting at school	16
Carbs in favourite foods	16
Getting ready for university/work/moving on	12
Teaching you to carbohydrate count	11
Special diets – gluten-free	11
Special diets – cholesterol lowering	9
Getting ready for an insulin pump	8
Special diets – weight loss	7
Special diets – vegetarian	6

Results

Completed surveys were obtained from 100 respondents (83 parents and 17 CYP). The return rate for the survey was 24.8%. It is not known whether more responses would have been collected if the software had allowed this.

Thematic analysis was used to group topics together. Results from questions 2–6, concerning the advice that respondents wanted from their dietitian, are presented in *Table 1*. The greatest

Table 2. Methods of dietetic support ranked in order of interest.

Method of support	Interest (% of respondents)
Meet when you have your three-monthly consultant appointment	53
Email contact	50
Telephone contact	28
Information available on our website	27
A once-a-year check-up – separate from consultant appointment	17
Come along for a separate dietetic-only appointment	6

Table 3. Potential activities while waiting for appointments, ranked in order of interest.

Topic	Interest (% of respondents)
Carbohydrate counting quizzes and games	27
Interesting ways to include more fruits and veg in your diet	21
Identifying foods high in fat and sugar and finding healthier alternatives	17
Managing diabetes while drinking alcohol (adolescent clinic only)	16
Understanding food labels	9

Table 4. Potential topics for group sessions ranked in order of interest.

Topic	Interest (% of respondents)
Advanced bolus options	34
Sports days and managing exercise	33
Preparing for secondary school	20
Healthy eating	16
Cooking sessions	10
Carbohydrate counting	9
Preparing for university	9
Getting control of your weight	7

interest was in management of exercise, followed by areas related to the management of specific foods and situations. Themes identified in the additional comments by respondents included "teaching CYP to count carbohydrates for themselves", "ethnic meal carbohydrate counting", "counting carbohydrates while away or on activity holidays", "low-carbohydrate diets" and "fat and protein counting".

Question 7, which asked about the specific timing and type of dietetic contact, was answered by 76 respondents. Of these, only 4% preferred a separate annual review appointment.

Question 8 identified that the majority of respondents indicated a preference for having dietetic review as part of the multidisciplinary clinic (*Table 2*).

The responses to question 9, which concerned educational activities to do whilst waiting for appointments, are presented in *Table 3*. There was a lower level of interest in more general food and health educational activities, while carbohydrate counting exercises were the most popular.

Table 4 presents the responses to question 10, which addressed potential topics for group educational sessions. The most popular topics for these were advanced bolus options and exercise management.

Additional comments on questions 9 and 10 revealed that parents were interested in tools to help and encourage their children to count carbohydrates, as well as in understanding food labels and managing on school residential trips.

Discussion

The BPT has helped to ensure that dietetic time is made available to CYP with diabetes; however, it does not specify how the dietetic service should be delivered, the quality of the service provided, outcome measures or what a dietetic review should entail. An annual review can often be perceived by CYP as a "summons" to see the dietitian, to discuss an agenda set by the dietitian. Therefore, providing services that parents and CYP want to regularly engage in and which meet the CYP's developmental needs is important.

Dietetic contact

This survey revealed that most parents and CYP wanted to receive dietetic education as part of

their MDT clinic review, and not as a separate appointment.

It makes sense that patients' needs can be better met if they can access support whenever needed rather than waiting for an annual review. Diabetes is a burden in itself and not all families have the time or resources to be able to attend additional appointments; therefore, alternative methods of contact and education should be available. The preferred methods of contact with the dietitian perhaps reflect the fact that this survey was conducted within a tertiary CYP diabetes service whose patients cover a wide geographical area; therefore, it is understandable that methods of contact that reduce travelling time and can be carried out remotely are preferred.

This highlights the importance of making the most of MDT clinic contacts and being accessible between clinics via other methods, such as email, telephone and websites. Services should therefore be organised to ensure that all patients have access to sufficient dietetic support within the MDT clinic.

Dietetic content

There is often a misconception that the dietitian's only role is to tell CYP what they should and should not eat. This survey aimed to highlight the broad range of areas that diabetes dietitians may be able to support CYP and their parents in.

The highest scoring area for advice and support requested from the dietitian was exercise management. This is in line with the findings of a patient survey in the US carried out by JDRF (2016), which identified exercise management as one of the areas in which people with type 1 diabetes felt the least supported by healthcare professionals. Quirk et al (2014) also found that parents in the UK do not always feel supported by healthcare professionals with managing exercise. Similarly, healthcare professionals acknowledge the need for further training and resources to be able to support young people undertaking exercise (Quirk et al, 2015).

After exercise, parents' and CYP's top areas of interest were getting a better HbA_{1c}; managing difficult situations, such as using advanced bolus options and insulin timing to manage foods such as pizza and takeaways; and understanding glycaemic index and particular areas of carbohydrate counting, such as eating out, making carbohydrate counting quicker and easier, and the use of apps and websites. New technology has improved awareness of how these situations impact blood glucose levels and provides the tools to manage them. The large proportion of responses relating to the management of more complex mealtime situations fits with the increased uptake of intensive therapy, insulin pump management and continuous glucose monitoring that has occurred in recent years.

It is likely that the topics identified as being the most important reflects the proportion of the clinic population using insulin pump therapy at UCLH. Carbohydrate counting and bolus insulin management is essential to improve outcomes both on pump therapy and with multiple daily injections. Diabetes management is enhanced by greater understanding of the more difficult situations to deal with (e.g. exercise, advanced boluses with different foods) and new, emerging areas of interest (e.g. fat and protein counting).

Healthy eating was also an area of interest but ranked lower than other areas. As overall composition of diet is an important part of longer-term glycaemic management and outcomes (Nansel et al, 2016), it is important to think about why "healthy eating" is not seen as a higher priority. There is evidence that diets higher in saturated fat are associated with greater insulin resistance and, therefore, greater insulin requirements (Smart et al, 2013; Wolpert et al, 2013), as well as worse management outcomes (Nansel et al, 2016).

Studies in the US and Europe provide conflicting reports on how "healthy" the diets of children and adolescents with type 1 diabetes are (Rovner and Nansel, 2009; Maffeis et al, 2012, Mehta et al, 2014). Education about food choices to improve both glycaemic management and longer-term health remains a key area of nutritional management. Reinforcing this message regularly is important and could be done as part of an annual review. Alternative methods for delivering "annual review" appointments to ensure they are patient-centred or finding ways to reinforce key messages during MDT clinics could also be considered. For example, at UCLH

Summary of findings

1. The majority of respondents to this survey wished to have their appointment with the dietitian at the same time as their multidisciplinary clinic review.
2. Remote communication – for example, via email or telephone – was also requested.
3. The most popular dietetic content was exercise management, followed by topics related to the management of specific foods and situations.
4. Regarding potential dietetic activities while waiting for appointments, carbohydrate counting quizzes were the most popular.
5. The most popular topics for group education sessions were advanced bolus options and exercise management.
6. However, respondents generally expressed low levels of interest in both group education and educational activities.

Page points

1. This survey was carried out at a large tertiary centre covering a wide geographical area; therefore, some of the findings may reflect the fact that the participants wanted to attend as few appointments as possible.
2. It is recommended that other centres conduct similar surveys to determine the views of their clients and develop their services.
3. There was a level of interest in all topics and methods of contact; therefore, a varied range of activities and methods of contact to suit all requirements is required.

we offer all patients the opportunity to meet with the dietitians at every MDT clinic, as well as the option to book additional dietetic clinics. Those who are not seen are sent "top tips" on popular topics highlighted by this survey.

Delivery of education

The respondents to the survey expressed low levels of interest in both group education and educational activities. Where interest was expressed, the desired topics reflected those previously identified.

The development of structured education has focused on delivery of education in group settings, and group education has been shown to increase self-efficacy and wellbeing (Murphy et al, 2011). Practically, group education sessions offer a way to reach greater numbers of families and young people. The reasons that group education did not generate higher-scoring responses may be due to the profile of the parents and young people who responded. Our patients cover a wide geographical area and, therefore, tend to prefer to limit the times in they have to travel. However, the majority of people who completed the survey accessed it via the online link distributed by the Families with Diabetes parent support group. It could be assumed that people who access these groups are more motivated, whereas those who would benefit more from group engagement may have been non-responders.

Engagement in group sessions is often poor, and this finding needs to be explored further to develop and deliver services that meet the needs of the clinic population. Smaller, local clinics may find it easier to organise and attract more interest in group clinics. The timing of delivery of group education is also important; for example, targeted at specific important milestones, such as in preparation for the transition to secondary school, when young people begin to take on more responsibility for their own care, including carbohydrate counting independently.

It should be noted that there was a level of interest in all topics and methods of contact, although some were more popular than others. This shows that "one size does not fit all" and highlights the importance of having a varied range of activities and methods of contact to suit all requirements.

Study limitations

This survey was limited by the number of questions that could be asked and the number of people who were able to respond. However, the questionnaire was designed to be quick and easy to complete, and it was felt that 10 questions were sufficient, as more may have been off-putting.

Overall, 83% of respondents were parents and 17% were young people. The way that the survey was distributed may have contributed to the greater proportion of parents responding to the survey, as the majority of respondents accessed the link to the questionnaire via online parent support groups.

Demographic information was not collected; therefore, it was not possible to ascertain how representative the sample of respondents was of the whole clinic population or those of other diabetes services. It could also be argued that the clinic at UCLH is not a typical clinic; therefore, repeating the survey across the wider network may be of value to establish what CYP and families want from dietitians as part of their diabetes management. Future surveys would need to explore ways to increase user engagement and obtain a wider sample of both parents and CYP from the service. There are a number of possible solutions; for example, having a researcher present at clinics to conduct the survey may be a better method to gain a wider sample of both parents and CYP.

Such surveys should particularly target non-responders and those who are hard to reach. Attempting to reach these groups is particularly important as, often, their views and opinions are not captured, further increasing the difficulty in reaching these patients.

Conclusions

Although this survey has its limitations with regard to being a representative sample of parents and CYP, it provides valuable information to inform the dietitian of areas where the service can be developed and improved, topics for continuing professional development and areas where further research is required. It is important to ensure that all parents and CYP are aware of the role of the dietitian and how the service can be accessed,

and to ensure that the service meets their needs, which this survey aimed to achieve. To the author's knowledge, there has been no survey of this kind carried out before. The results of this questionnaire have been used to develop the dietetic service at UCLH in a variety of ways, including the following:

- Patient information leaflets have been developed on the use of advanced bolus options and adjusting dose, bolus type and timing to deal with tricky foods, based on the latest evidence. These leaflets are accessible via the team's website.
- For people who are not seen by the dietitian during MDT clinics, lists of "top tips" covering the popular topics have been added to clinic letters. These topics change on a quarterly basis.
- Mini education sessions have been developed on various topics that can be used within clinics, such as building confidence with carbohydrate awareness and counting, healthy eating and alcohol management.
- Discussions have taken place to potentially carry out the survey across the whole local network.
- Skype clinics are being trialled as alternative type of remote communication.
- A regular dietetic-led sports and exercise management clinic has been initiated.

It is important that all dietitians working with CYP are competent in exercise management and advanced bolus options for difficult foods and fat and protein counting. These findings also highlight the need for further research in these areas to better inform clinical management. ■

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