POSITION STATEMENT

DiABETES UK
CARE. CONNECT. CAMPAIGN.

Title	Date
Adult learning within Self Management and Support	June 2014

Key points

- Supported self management is key to the successful day to day management of diabetes, putting the person with diabetes at the centre of their care, working in partnership with their health care professional team. Any self management approach must include personalised care planning, psychological and emotional support and access to information and education as essential elements.

- Education can be defined as the act or process of imparting or acquiring particular knowledge, competences or skills. Any experience that has a formative effect on the way one thinks, feels, or acts may be considered educational. Education also needs to reflect the different learning styles of people with diabetes and meet their own educational needs.

- Diabetes UK believes that structured patient education meeting NICE standards is the standard towards which all people with diabetes should be directed, at a time when it is most appropriate for them but that few courses can be shown to fully meet this standard.

- Diabetes UK states structured patient education meeting NICE standards should be available to all people with diabetes, not only at the time of diagnosis but on an ongoing basis throughout their journey with the condition.

- Such education sessions should be provided in as accessible manner as possible, as part of routine care, considering the needs of people with diabetes. Such consideration should include physical access, timing of sessions (ensuring those who work full or part-time are not discriminated against) and opening sessions to carers/family.

- The term ‘education’ can be off-putting to some people with diabetes and therefore we need to review the terminology used to encourage take up, considering terms such as “skills training”, “diabetes awareness learning”, “diabetes support sessions” or “diabetes information exchange” which may be more user friendly.

- Data shows that not all people with diabetes wish to undertake formal education courses. Only 12% of people newly diagnosed with Type 2 diabetes were offered structured education in 2011/2 (1). However, for people with both Type 1 and Type 2 diabetes, only 25% of those offered structured education, chose to take it up.

- Diabetes UK believes that a different approach is needed to meet the needs of more people with diabetes and to ensure they have access to information and education about their condition. This should not be at the expense of structured education, but to supplement it and encourage more people, who would not be initially open to learning, to get into it. Diabetes UK generally supports the position of Diabetes Education Scotland which refers to three levels of education and sees patient education as an ongoing process which may be referred to as following a spiral curriculum (2).

- Access to learning should be discussed and recorded as part of the care planning process.

- Diabetes UK therefore calls for appropriate educational initiatives to be funded and delivered to meet the needs of people at all levels and new initiatives to be developed where a need is identified. These should not only be aimed at the newly diagnosed but should provide ongoing educational opportunities for people at all stages of their diabetes journey

Introduction

Supported self management is key to the successful day to day management of diabetes, putting the person with diabetes at the centre of their care. Any self management approach must include personalised care planning, psychological and emotional support and access to information and learning as essential elements (3).

Education can be defined as the act or process of imparting or acquiring particular knowledge, competences or skills. Any experience that has a formative effect on the way one thinks, feels, or acts may be considered educational whether within or outside a formal education process. Education also needs to reflect the different learning styles of people with diabetes and meet their own educational needs.

However, data shows that not all people with diabetes choose to undertake formal education courses, possibly because of a lack of understanding of the need for such learning, and of the courses offered to the newly diagnosed in 2011/2, take-up was only about 25% for both people with Type 1 and Type 2 diabetes (1).

Diabetes UK therefore states that there is a need to reconsider both the language we use when talking about patient education, the timing and the approaches we take to providing it, accepting that 'one size doesn't fit all'.

Current situation

Since 2003 access to structured patient education has been recommended by NICE. The update to CG87, management of Type 2 diabetes (4), states that "structured education should be offered to every person and/or their carer at and around the time of diagnosis, with annual reinforcement and review" and that clinicians should "inform people and their carers that structured education is an integral part of diabetes care". The original technology assessment states that "it is recommended that structured patient education is made available to all people with diabetes at the time of initial diagnosis and then as required on an ongoing basis, based on a formal, regular assessment of need" (5). It also states that:

- educational interventions should reflect established principles of adult learning
- education should be provided by an appropriately trained multidisciplinary team to groups of people with diabetes, unless group work is considered unsuitable for an individual - Multidisciplinary teams providing education should include, as a minimum, a diabetes specialist nurse (or a practice nurse with experience in diabetes) who has knowledge of the principles of patient education and a dietitian.
- sessions should be accessible to the broadest range of people, taking into account culture, ethnicity, disability and geographical issues, and could be held either in the community or at a local diabetes centre
- educational programmes should use a variety of techniques to promote active learning (engaging individuals in the process of learning and relating the content of programmes to personal experience), adapted wherever possible to meet the different needs, personal choices and learning styles of people with diabetes, and should be integrated into routine diabetes care over the longer term.

The NICE Quality Standard 6 (6), states that a patient educational programme should meet five key criteria laid down by the Department of Health and the Diabetes UK Patient Education Working Group:

- Any programme should be evidence-based, and suit the needs of the individual. The programme should have specific aims and learning objectives. It should support the learner plus his or her family and carers in developing attitudes, beliefs, knowledge and skills to self-manage diabetes.
- The programme should have a structured curriculum that is theory-driven, evidence-based and resource-effective, has supporting materials, and is written down.
- The programme should be delivered by trained educators who have an understanding of educational theory appropriate to the age and needs of the

learners, and who are trained and competent to deliver the principles and content of the programme.
- The programme should be quality assured, and be reviewed by trained, competent, independent assessors who measure it against criteria that ensure consistency.
- The outcomes from the programme should be regularly audited.

Diabetes UK continues to support this approach and believes structured patient education meeting these standards should be available to all people with diabetes, not only at the time of diagnosis but on an ongoing basis throughout their journey with the condition, as part of their ongoing care.

However, despite these clear recommendations, ten years on access to structured patient education is still woefully poor. Although we accept that data quality around access to structured education is poor, data from the National Diabetes Audit 2011/12 (7), showed that there were no referrals to structured education recorded for eight CCG areas and almost half of CCG areas (47.8%) achieved referral rates of less than 10.0%. These figures compare to the national rate of 14.0%. Worryingly NDA data also shows that, even when educational courses are offered to the newly diagnosed, take-up rates are only around 25% (3). Access to ongoing education is not recorded in this data but anecdotally is very limited. Data from a survey of about 400 people with diabetes showed that 76% of people wanted to have access to ongoing learning (8).

Diabetes UK calls to action or Recommendations

New Approach

Although Diabetes UK is aware of many people who wish to access structured patient education and are unable to do so in their locality, these figures suggest that, for many people, the need to attend an education course is either unclear or felt to be unnecessary; the concept of 'diabetes education' in a group setting is off-putting; or other factors take precedence over attending an educational session, probably particularly connected with getting time off work.

In a study presented at Diabetes UK's Professional Conference in 2014 (9), 76% of people referred to one X-PERT programme failed to attend and expressed the main reasons for non-attendance as a lack of transport and working hours. The use of the term 'education' itself may also be off-putting to some people, who may have negative connotations of the word linked to their own school experience. Education should therefore be referred to as part of the supported self-management approach and terminology such as "skills training", "diabetes awareness training", "diabetes support sessions" or "diabetes information exchange" may be more user friendly. Results from the survey (9) above indicated that, of those who hadn't already attended any diabetes course, 31% did not express a wish to do so.

Diabetes UK believes that a different approach is needed to meet the needs of more people with diabetes and to ensure more people have access to information and education about their condition. This should not be at the expense of structured education, but to supplement it and encourage more people, who would not be initially open to learning, to get into it. Diabetes Education Scotland refers to three levels of education and sees patient education as an ongoing process which may be referred to as following a spiral curriculum (2).

Diabetes UK would generally support this approach and recognises the needs for different educational approaches at different stages in the diabetes journey.

Introductory Diabetes Education refers to education that is given at diagnosis of diabetes. This may be in the form of information, sign-posting to relevant educational tools or one to one discussion, often given by the healthcare team responsible for the person's care. This may also be education on specific skills which need to be acquired (such as carbohydrate counting in Type 1 diabetes).

Ongoing Diabetes Learning refers to education that is ongoing, throughout your life and normally relates to specific aspects which the person needs to learn more about as they become more confident living with their diabetes. This could include learning more in depth knowledge around diet or focusing on the management of a specific complication, if relevant, and could also include entirely peer led support and education initiatives

Standard Education refers to education that is delivered to a group of people. This would include structured patient education, meeting the NICE criteria.

The first two of these should act as a catalyst for people to work towards attending a Standard Education initiative but attendance at such a course should not be dependent on an individual having undertaken other learning opportunities if it would be suitable for them at that stage in their diabetes journey. Learning opportunities should be provided at the most appropriate point for the individual and should not be delayed unnecessarily. This is particularly true for the newly diagnosed who need relevant information and education at the point of diagnosis and they should not be told to wait until a suitable place on a course becomes available. Individuals who are reluctant to attend a Standard Education course should be offered and signposted to other educational opportunities which may be more appropriate for them at that time in their diabetes journey.

Diabetes UK therefore calls for appropriate educational initiatives to be funded and delivered to meet the needs of people at all stages and new initiatives to be developed where a need is identified. These should not only be aimed at the newly diagnosed but should provide ongoing educational opportunities for people at all stages of their diabetes journey. Such education sessions should be provided in as accessible manner as possible, considering the needs of people with diabetes. Such consideration should include physical access, timing of sessions (ensuring those who work full or part-time are

not discriminated against), opening sessions to carers/family and ensuring that sessions are tailored to the learning abilities of the individual.

Although the NICE recommendations highlight the involvement of a specialist nurse and dietitian as a minimum for any education course, evidence shows that peer education can be equally effective. A review of evidence in published studies into peer support (10) found that there were clinically and statistically significant improvements within-group and between-group changes with 83.3% of reports (using controlled designs) showing improvement (66 studies). The 14 diabetes specific studies showed a statistically significant average drop in HbA1c from 8.63 to 7.77% (71 to 61 mmol/ml) and one study, at least, showed a significant reduction in overall cholesterol and improvements in HDL and LDL (11). Peer education has also been shown to be cost effective (12).

Diabetes UK believes that peer led educational programmes should also be available as part of the educational arsenal.

Quality Assurance

All educational initiatives should be developed with the involvement of people with diabetes, to ensure they are appropriate and meet the needs of the specific community they are aimed at.

It would be inappropriate for all approaches, at each of the three stages, to have to demonstrate effectiveness through clinical trials and research. However, all educational initiatives should be able to demonstrate what people with diabetes will achieve by undertaking them and should have some measure of validation to demonstrate those outcomes. Although improved clinical outcomes are the gold standard, other outcomes are also relevant and valid. These could include Quality of Life indicators, PROMS, improved knowledge or improved confidence in self management.

All educational approaches should also consider the NICE standards when they are being developed including:

- specify the aims and learning objectives
- have a structured curriculum that is theory-driven, evidence-based and resource-effective, has supporting materials, and is written down.
- delivered by educators who are trained and competent to deliver the principles and content of the specific programme.
- should be quality assured and regularly audited.

Group education, if not undertaking its own quality assurance and audit, should be working with QISMET (Quality Institute for Self Management Education and Training) to demonstrate that they meet the Diabetes Self Management Education Quality Standard (6), launched in 2011.

Educational Approaches

Examples of educational approaches at each level.
Introductory Diabetes Education:

- One to one discussion about the basics of diabetes from a qualified HCP who has undergone training in diabetes
- Providing newly diagnosed people with Diabetes UK Companion Guides, followed up by a discussion with the person to assess their knowledge
- Signposting newly diagnosed people with Type 2 diabetes to Type 2 Diabetes and Me online interactive programme followed up by a discussion with the HCP to assess learning
- Signpost to Diabetes UK Living With Diabetes Day

Ongoing Diabetes Learning:

- Group work with Healthyi Conversation Maps (a facilitated discussion tool) about specific areas of diabetes management
- Open University online course on diabetes
- Carbohydrate counting tool available from Bournemouth Education Centre online
- Diabetes UK's Peer Support Programme currently being piloted
- MyDiabetesMyWay online resources in Scotland

Standard Education:

- Take part in group education programme that meets the NICE standard e.g. DAFNE, X-PERT or DESMOND or the APEDS (Assessment of Patient Education in Diabetes in Scotland) standard in Scotland.

Recommendations

Self-management is essential to diabetes care. It means people with diabetes need to understand their condition and be motivated to keep up their day-in-day-out management over a diabetes journey that can last decades.

Our fundamental recommendation is that diabetes education is about learning over a lifetime offering a variety of different ways that people with diabetes can learn. This is not about one form of learning being available, but about encouraging people to want to learn more, taster sessions to encourage people to get the most out of their care and provide different options that work for them, whether in groups or one-to-one, face to face or online etc.

The existing structured education courses are a key part of this lifelong learning. People with diabetes need:

- high quality courses, which are appropriately quality assured, offered to them both at the time of diagnosis and throughout their diabetes journey
- the benefits of attendance need to be clearly and compellingly explained

- courses designed around their needs, so they are conveniently timed and located while being tailored for different learning styles, personal circumstances and cultural backgrounds.

Such changes will bring about a major improvement in the support for people with diabetes. But they are not sufficient by themselves. It is highly unlikely that structured education courses will be accessed by everyone who needs to be better informed about their diabetes, and many people who have already undertaken a structured education course may only want a 'top-up' without repeating the full course again.

Therefore new, shorter and more informal ways of learning about diabetes are needed as well as the current structured education.

All need to raise awareness of the importance of learning as part of managing diabetes and the importance of engaging more people with diabetes in their own care.

Diabetes UK will:

- develop and deliver new services such as peer based support and learning and Living with Diabetes Days to help meet this need as another form of support and learning.
- campaign for the needs of people with diabetes to have access to quality education and raise awareness of the importance of people with diabetes accessing learning throughout their life with diabetes.

Those who commission services across the UK need to ensure that learning opportunities at all stages of diabetes education are available for all people with diabetes so that they can engage with learning that is appropriate for their needs. They need to ensure that people with diabetes are encouraged to take up those opportunities and should have systems in place to check both effectiveness of programmes and uptake and to understand local barriers to people taking up sessions.

National decision makers need to ensure there are appropriate metrics in place that can measure how well people are having their educational needs met. This needs to be an appropriate part of their performance management. Current recording of education offered and taken up for the newly diagnosed, as part of the QoF, is only one such metric and others will need to be developed.

Conclusion

Diabetes UK believes that a different approach is needed to meet the needs of more people with diabetes and to ensure more people have access to information and education about their condition. This should not be at the expense of structured

education, but to supplement it and encourage more people, who would not be initially open to learning, to access it.

Accordingly Diabetes UK sees patient education as an ongoing process which may be referred to as following a spiral curriculum, assessing individual circumstances and offering different learning approaches at different stages in the journey of the individual with diabetes .

Diabetes UK therefore calls for appropriate educational initiatives to be funded and delivered to meet the needs of people at all levels and new initiatives to be developed where a need is identified. These should not only be aimed at the newly diagnosed but should provide ongoing educational opportunities for people at all stages of their diabetes journey. Access to these learning opportunities should be recorded in the individual's medical record as part of the care planning process, including the decisions individuals make about whether to attend or not.

References

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