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Informal and flexible approaches to self-management education for people with diabetes

Report commissioned by Diabetes UK

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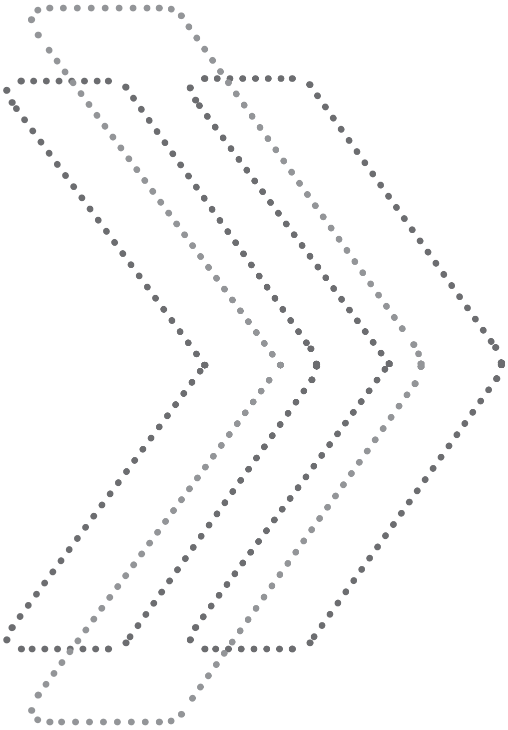

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This report was commissioned by Diabetes UK. It is based on independent research conducted by The King's Fund and the conclusions reached are those of the author.

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Executive summary

Background

Education is critical in giving people with diabetes the knowledge and confidence they need to manage their condition effectively on a day-to-day basis. There is good evidence that structured education can help to support the stabilising of blood glucose levels and minimise the risk of complications (Diabetes UK 2015). The value placed on self-management education is reflected in National Institute for Health and Care Excellence (NICE) guidelines, which recommend that all people with type 1 and type 2 diabetes are offered the opportunity of attending a high quality, structured education programme within a certain period of time following their diagnosis (NICE 2015b, 2015c).

Despite this, uptake of structured education courses among people with diabetes is extremely low – in England, just 0.9 per cent of people with type 1 and 3.8 per cent of people with type 2 diabetes who are newly diagnosed (HSCIC 2014). A recent investigation by the All-Party Parliamentary Group (APPG) for Diabetes identified a range of barriers to uptake and provision that may help to explain these figures, ranging from poor quality referrals from health care professionals to poor marketing. The APPG also highlighted a set of practical factors, such as the location and timing of courses, and the difficulty some people have in getting the necessary time off work. In addition, some people are less engaged with their health than others (Hibbard and Gilburt 2014) and therefore are less likely to take advantage of the education opportunities on offer.

Among its proposals to help to address these barriers, the APPG called for a more holistic approach to patient education. It recommended that the NHS Planning Framework ensure that all local areas put in place plans for diabetes education, including a range of less formal approaches to operate alongside high quality, structured education programmes (APPG for Diabetes 2015).

Against this background, Diabetes UK commissioned The King’s Fund to identify the main approaches being used in informal self-management education and, as far as possible, to determine their effectiveness. The King’s Fund’s work comprised a review of the available literature and conversations with a number of stakeholders with relevant expertise.

Approaches to level two education

Building on the approach taken by Diabetes Scotland, Diabetes UK has adopted a broad framework that considers patient education on three levels. The first level refers to one-to-one advice from health care professionals, while level three is used to describe structured education that meets NICE guidelines. The term ‘level two education’ is used to describe a wide range of self-management education initiatives that are typically less formal than structured education programmes and that support ongoing learning.

Within the context described above, level two education seeks to increase the number and range of people who access self-management education by offering a variety of options. Like all self-management education, level two initiatives ultimately aim to provide individuals with the knowledge and skills they need to manage their condition effectively on a day-to-day basis, leading to a better quality of life and a lower risk of complications.

Despite the wide variety of formats adopted, it is possible to group these initiatives into three broad categories.

- **Face-to-face group-based education** – these can be similar to traditional structured education courses but are typically shorter in duration (perhaps a single one- or two-hour session). They often focus on a particular aspect of self-management. They may also rely on a less formal, more discursive format than structured education sessions.

- **Peer-based approaches** – these can take a range of forms, including online peer networks, group-based peer sessions and peer tutor programmes. The characteristic common to each of these approaches is the emphasis on sharing knowledge and experience between people who share the same condition.

- **Technology and internet-based approaches** – this category includes a range of approaches, such as interactive websites and modular training online. Technology and internet-based approaches are often used in peer-support approaches, for example through telephone-based peer programmes.

Outcomes

While a review of the literature provided limited evidence on the uptake of level two education, it was clear from conversations with stakeholders that those initiatives that are in place are well-attended. They also appear to be met with high levels of satisfaction from users – a message that came through in both stakeholder conversations and the literature. It is also clear that approaches that adopt an online format have the potential to significantly increase the number of people accessing education.

Determining the outcomes of the different approaches is more challenging. This is partly due to the inherently informal nature of level two education, which means that systematically collecting information on clinical outcomes – for example, blood sugar levels – is impractical. Instead it is more helpful to measure these initiatives in terms of their ability to achieve a number of ‘psychosocial outcomes’, such as patient empowerment, self-efficacy (the individual's belief in their ability to carry out certain actions), behaviour change and quality of life. All rely on patient reporting and are most meaningful when information is collected before and after the intervention.

Few of the initiatives described by stakeholders routinely collect outcome data, and much of the evidence available is anecdotal. Also important to note is that conversations were held predominantly with those with knowledge of or an involvement in successful initiatives. However, the literature provided some evidence on the aspects of the different approaches, suggesting that many of these (peer-based initiatives in particular) can increase the confidence and self-efficacy of people with diabetes. There is also evidence that they can support behaviour change, which in turn can help to minimise the risk of complications and improve quality of life.

Conclusions and further work

Conversations with stakeholders suggest that a number of informal approaches to patient education are being used alongside structured programmes. These range from online resources with potentially infinite reach to local schemes targeted at a particular section of the population. However, the picture is one of local variation, with initiatives being developed on an ad hoc rather than a consistent basis.

It is clear that each of these approaches can help to improve overall access to education, and that they are valued by users. Although the formal evidence is limited, and information on users prior to the intervention is not always available, there are also indications that level two education can be associated with positive outcomes, particularly in terms of patient engagement and self-efficacy.

This paper provides an initial insight into the different approaches being used in level two self-management education. Cataloguing the initiatives taking place across the United Kingdom (and elsewhere) more systematically would help to provide a comprehensive picture of the different formats this education can take, and how it can be best designed to meet the needs of particular groups. In principle there is nothing to prevent any of the individual initiatives described in this report from being implemented in other areas with equal success. Increased opportunities for commissioners and education providers to share their experiences and learn from individual projects could help to encourage this. Further work to understand informal approaches to education for people with other long-term conditions would also be beneficial.

A clear message from both a review of the literature and conversations with stakeholders was that people with diabetes are best served by having a menu of education options to choose from (in addition to support from health care professionals). This allows individuals to identify those which are best suited to their needs, lifestyle and learning style, and should help to increase the range of people who are engaged. However, it is also important to recognise that some people are less engaged in their health than others and may choose not to participate in many different forms of self-management education, even where a range of options is provided. Information on the characteristics of those accessing education should be used to help to understand their effectiveness and inform the development of new approaches.

More detailed information on outcomes is also important to help to focus future efforts to expand the self-management education offer. Bearing in mind the practical challenges to systematically collecting information on clinical outcomes, a first step might be to determine whether any of the existing frameworks for collecting patient-reported outcomes, which are highlighted in this paper, would be appropriate for collecting information on a more regular basis.

Introduction

This paper sets out the findings of a study commissioned by Diabetes UK on approaches to level two diabetes self-management education. It brings together the evidence in the literature and from conversations with stakeholders in order to: describe the main approaches to level two education; outline the evidence available on the effectiveness of each approach; and present the key conclusions and areas for further work.

Background

Diabetes and self-management education

More than 3.5 million people in the United Kingdom have been diagnosed with diabetes, a chronic condition in which the body produces no insulin or insufficient levels of insulin, leading to high levels of sugar in the blood. There are a number of different types of diabetes, but the most commonly applied distinction is between type 1 diabetes, in which no insulin is produced, affecting approximately 10 per cent of people with diabetes, and type 2, where not enough insulin is produced, or it is ineffective – this affects 90 per cent of people with diabetes. Estimates suggest that the number of people with diabetes in the United Kingdom has been increasing by approximately 5 per cent each year (NAO 2015), and that the cost to the NHS by 2035 will be £16.9 billion, accounting for 17 per cent of the NHS budget (Hex *et al* 2012)

As with anyone with a long-term condition, self-management is important for people with diabetes; it is estimated that 99 per cent of all diabetes care falls to the individual (APPG for Diabetes 2015). Managing diabetes well on a day-to-day basis can help to reduce the risk of complications and maximise the quality of life for the individual. Within this context, self-management education has an important role to play in helping people to develop the knowledge and confidence they need to manage their condition. There is good evidence that structured education helps to support the stabilising of blood glucose levels and can help to minimise the risk of complications (Diabetes UK 2015).

Challenges with current education provision

In recognising the role of education in successful self-management, policy in the United Kingdom has sought to promote the development and implementation of quality-assured, structured education programmes for people with type 1 and type 2 diabetes. This is reflected in NICE guidelines, which recommend that within a certain period of time following their diagnosis, all diabetes patients be offered a structured education programme that meets a defined set of criteria. The NICE Quality Standard for diabetes in adults requires evidence that local arrangements are in place to support this (NICE 2015a).

Unfortunately, however, evidence shows that in practice uptake of structured education courses is extremely low. The National Diabetes Audit 2012–13 found that in England only 0.9 per cent of people with type 1 and 3.8 per cent of people with type 2 diabetes who are newly diagnosed attend group-based diabetes education (HSCIC 2014). An investigation by the APPG for Diabetes identified a number of factors that help to explain these figures, such as people not being offered structured education, limited information being available on the content or purpose of courses and, for some of those who do seek referral, long waiting times. Other barriers to uptake include the location and timing of courses, a major barrier for some people, and the failure of courses to take patient preferences into account in their design and content. The APPG for Diabetes review also highlighted several barriers to provision, including pressure on commissioning budgets, and a lack of awareness (or the undervaluing) of available education on the part of health care professionals. This led to either too few referrals – or ones where the benefits of attendance are not explained (APPG for Diabetes 2015).

It is important to note that the characteristics of users also play a role in uptake. There is evidence that up to 40 per cent of the population at large have low levels of patient activation – a behavioural concept that is linked to individuals' understanding of their role in the care process and the degree to which they feel capable of fulfilling that role. People with low levels of activation may not take advantage of any education opportunities, despite the range on offer, although tailoring programmes can help to address this (Hibbard and Gilburt 2014).

The APPG's investigation concluded that a more holistic approach to self-management education is needed, with much greater flexibility in terms of content and delivery. This is particularly important in ensuring 'lifelong learning' for people with diabetes. The APPG for Diabetes recommended that the NHS Planning Framework ensure that all areas put in place plans for diabetes education, including a number of less formal approaches to operate alongside structured education programmes (APPG for Diabetes 2015).

Diabetes UK fully supports this ambition for a wider range of learning opportunities. It is clear that while high quality, structured education remains key to supporting individuals with diabetes, there is a need to address some of the barriers to uptake identified above, including by broadening the education offer and providing people with a range of flexible learning opportunities, on a more consistent basis.

Methodology

Project objectives and scope

The purpose of this study was to identify the main approaches being used in the provision of informal and flexible diabetes self-management education (described by Diabetes UK as ‘level two’ education). As far as possible, the study sought to determine the effectiveness of the different approaches and, drawing on the findings, to highlight areas that may benefit from further research.

The focus of the work was on self-management education for adults (people aged over 18 years old) with either type 1 or type 2 diabetes. Although the study considered a number of initiatives taking place across the United Kingdom, it was not intended to be an exhaustive review of all relevant programmes.

Methodology

The study comprised a review of the literature and conversations with a number of stakeholders.

Literature review

A review was undertaken of UK and international literature (English language only) relating to informal approaches to self-management education. This included academic and grey literature as well as some unpublished material. It also included some material relating to other long-term conditions, where there was potential learning for diabetes education.

Stakeholder conversations

The study also included a series of informal conversations to draw on the expertise of a number of stakeholders. A total of 12 conversations were held with a range of stakeholders including education providers, clinicians, self-management education experts and researchers.

These conversations were used to identify any additional written material (including unpublished material) to incorporate into the literature review, and to support an informal case study approach by drawing on information from specific initiatives within the United Kingdom. Within this context it is important to note that many of the stakeholders involved in the study were identified on the basis of their knowledge of or involvement in successful or well-developed initiatives.

What is 'level two' self-management education?

Diabetes self-management education is a means of increasing people's knowledge of their condition and the ways in which they can manage it on a day-to-day basis, minimising the risk of complications. It also seeks to build the individual's confidence in their ability to take on this role. Building on the approach taken by Diabetes Scotland, Diabetes UK has adopted a framework that considers patient education on three separate levels.

Level one education describes the provision of information and advice on diabetes management on a one-to-one basis. This is typically provided by a health care professional at the time of diagnosis.

Level three education refers to structured education programmes such as DAFNE (Dose Adjustment For Normal Eating), for people with type 1 diabetes, and DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed) for people with type 2 diabetes. These programmes meet a set of nationally agreed criteria that are set out in NICE guidelines, including an evidence-based curriculum, the use of trained educators, quality assurance of teaching standards and regular audit (NICE 2015b, NICE 2015c). QISMET (the Quality Institute for Self-Management Education and Training) has developed the Diabetes Self Management Education Quality Standard offering providers a means of demonstrating that they have met the relevant NICE criteria.

NICE guidelines recommend that individuals be given the opportunity to attend a structured education course within a certain period of time after their diagnosis. These courses offer a broad range of topics relating to diabetes self-management, as set out in the curriculum, and are most commonly delivered face-to-face in a group setting by a trained professional. Current structured education typically involves a number of sessions over a period of several days or weeks; however, some structured education courses are beginning to adopt a different format. Mapmydiabetes is an example of a QISMET-accredited provider offering comprehensive, online education that meets the NICE guidelines, apart from the use of a face-to-face trained educator.

Level two education is perhaps the most difficult to define. Level two initiatives are less formal than structured education programmes and, rather than being targeted at those who are newly diagnosed, these initiatives aim to support ongoing learning for people with diabetes. Level two initiatives are often focused on a particular aspect of self-management or aimed at a particular group of patients. They can take a wide variety of formats from classroom-based learning to peer support approaches. However, their defining characteristic is that they offer the individual the opportunity to learn about self-management in a flexible and informal way.

Approaches to level two self-management education

Overview

Conversations with stakeholders indicated that a significant amount of level two education is being undertaken across England. They also suggested that a wide variety of approaches are being adopted; initiatives tend to be developed locally and are often tailored to the particular needs of a specific population.

As anticipated, a review of the literature provided little formal evidence on the nature and role of level two-type approaches to diabetes self-management education. However, it did offer an insight into some aspects of these initiatives, for example, the involvement of peers or the use of online formats. These appear to be similar to approaches being taken to self-management education for people with other chronic conditions.

Drawing on the literature and stakeholder conversations, it is possible to group level two initiatives under three broad headings, although inevitably a number of examples fall within more than one category. This section provides a description of these groups, as well as a number of examples for each.

Face-to-face group-based approaches

Many level two initiatives involve bringing people with diabetes together physically to learn about their condition from a trained professional. Some are classroom-based and can adopt a similar teaching style to structured education programmes. However, level two initiatives tend to be shorter in length and are often focused on a particular aspect of self-management or targeted at a particular population group. Others adopt a less formal teaching style and rely more heavily on informal discussion within the group.

Diabetes UK runs a number of events that fall into this category. This includes Living with Diabetes Days, education days aimed at people with type 2 diabetes, as well as a series of Care Events, which are held for one day or over a weekend for adults with type 1 diabetes (Diabetes UK also runs these events for children with diabetes). Both events cover a broad range of topics relating to self-management. Examples of initiatives with a more specific focus include the Lambeth Food and Diabetes Group workshop, a two-hour workshop that concentrates on dietary advice, and the Diabetes Club for Bengali women in Tower Hamlets in London. The Diabetes Club sessions last for approximately an hour, and include advice for people with type 2 diabetes on health activities as well as 30 minutes of exercise with a qualified trainer.

The literature review identified one initiative that sought to use patients' visits to a screening clinic for eye disease as an opportunity for very informal group education. In this example, diabetes educators acted as facilitators in the clinic's waiting areas to spark discussions about self-management, with the topics covered being determined by participants' questions (Gillard *et al* 2004).

Peer-based approaches

Peers can take on a variety of roles in self-management education (Heisler 2009). At its simplest, a peer-based approach involves bringing people with a particular health condition together to share their experiences of managing that condition and to swap information and advice. This may happen within a group environment or on a one-to-one basis, and the format for communication can range from face-to-face conversations to telephone calls and online discussions through forums. These initiatives sometimes involve matching individuals on the basis of their background and experience, or according to their track record in self-management. Alternatively, they can involve a more ad hoc group of individuals, such as patients in a waiting room, as in the example described above (Gillard *et al* 2004). The format of peer-based sessions is often very informal involving unstructured conversations between individuals, the content and topics covered being determined by the participants. One example identified in the literature involved a 'story-telling' approach (Greenhalgh *et al* 2009).

Other approaches involve a more formalised peer role. These schemes tend to identify a group of people with diabetes to take on a peer tutor or peer adviser role. These people are trained in key aspects of self-management and are given access to advice from health care professionals so that they can provide support and advice to an individual or a group of peers (Baksi *et al* 2008).

The defining feature of peer-based approaches is that the primary source of information is people with direct experience of managing the same condition as the beneficiaries, either as a patient or through the experience of supporting a family member. As such, initiatives tend to focus on providing encouragement and increasing patients' morale, and do not provide the same level of clinical advice as professionally led initiatives.

Examples of peer-based initiatives include online discussion forums, such as the one run by Diabetes.co.uk, and Diabetes UK's peer support programme, which enables people with diabetes to talk, either by phone or email, to support volunteers with direct experience of managing diabetes. These approaches are widely used for people with other chronic conditions, such as the support groups set up for stroke survivors, local 'breathe easy' groups for those living with a lung condition, and local support groups for people with epilepsy. Another example is the Diabetes Befriending project in Tower Hamlets, which involves the recruitment of a number of volunteer 'befrienders' to befriend local people with type 2 diabetes to give advice on diet and exercise, as well as information on local services. Similarly, the British Lung Foundation runs a pen-pal scheme to help people with lung disease share their experiences and advice.

The literature review identified one study of a diabetes education initiative based in Newham in London, which adopted a 'sharing stories model' aimed at minority ethnic groups. Participants were encouraged to choose a theme for each session, such as medication or dealing with doctors, and come prepared to share personal stories relating to that particular issue (they also had the option of inviting a specialist to come and answer their questions) (Greenhalgh *et al* 2009).

The literature review also identified a few examples of initiatives involving some form of peer trainer (Baksi *et al* 2008; Heisler 2009). This included a peer tutor scheme in the Isle of Wight (Baksi *et al* 2008), and a study based in Cambridgeshire comparing the role of 'peer support facilitators' in one-to-one and group contexts (Simmons *et al* 2015).

Technology and internet-based approaches

Technology and the internet can be used as the basis for different types of level two education. Peer-based approaches in particular frequently rely on the internet, for example, for discussion forums or email exchanges. The literature review also identified several examples of peer-based support that took place predominately or exclusively over the phone (for example, Dale *et al* 2008).

Patients are also able to access a wide range of learning materials online. In addition to information pages provided by the NHS and a number of diabetes charities, there are several informal courses available online which enable individuals to learn and test themselves on information relating to different self-management topics. More recently there has also been a proliferation of apps relating to diabetes self-management, although the quality of the information they provide isn't easily monitored (this applies to some online material too).

Examples of technology and internet-based approaches (in addition to the peer-based approaches described above) include Type 2 Diabetes and Me, an informal online course run by Diabetes UK, and an online education course provided by HeLP-Diabetes. HeLP-Diabetes' course includes eight sections each covering a different topic, but there is no curriculum and therefore it is up to the user to decide which sections they access. Similarly, Epilepsy Action Learning runs a range of online courses for people with epilepsy, while the Epilepsy Foundation in the United States has a series of webinars on its website providing information on specific issues including those relating to self-management.

In recent years comprehensive self-management programmes traditionally provided face-to-face have also begun to offer their content online. For example, The Expert Patient Programme designed to support individuals living with a chronic condition was traditionally delivered in small groups (2.5 hours a week for six weeks) and is now available in an online format. Similarly, The Heart Manual, a home-based rehabilitation self-help package which has been shown to be as effective as hospital-based rehabilitation programmes, is now provided in a digital form.

There are also examples of comprehensive education for diabetes provided online. Mapmydiabetes is a QISMET-accredited provider that offers the full structured education curriculum in an online format. Unlike traditional structured education that is classroom-based and led by a trained educator, Mapmydiabetes makes use of an online format in which users have individualised accounts. This means it can deliver self-management education on an ongoing basis, including by 'pushing' topics that are most relevant to the particular user.

Determining the effectiveness of level two self-management education

Level two self-management education has two broad objectives: to increase overall uptake of self-management education, and to help people manage their diabetes as effectively as possible, as evidenced by a set of outcomes. This section outlines these objectives in more detail, along with approaches to measuring the success of level two initiatives in each area.

Increasing access to self-management education

A fundamental objective of level two education is to increase the overall number of people with diabetes who receive some form of self-management education. By offering people flexibility in the way that they access education, level two initiatives seek to broaden the education offer beyond structured courses and appeal to a wider range of people. This includes targeting specific groups where uptake of structured education is particularly low.

Because level two education does not provide the full curriculum of self-management education, it remains important that as many people with diabetes as possible receive the comprehensive education offered by structured education programmes. There is evidence in the literature to show that longer periods of education are associated with better outcomes (Steinsbekk *et al* 2012; Norris *et al* 2002). Within this context, level two initiatives can play a valuable role in acting as a 'gateway' to structured education courses; raising awareness of their importance and signposting users to appropriate courses.

A further objective of level two education is that it promotes ongoing learning for people with diabetes. For those people who have attended a structured education course, level two education initiatives provide the opportunity to refresh or update knowledge, or to increase knowledge or skills in relation to a particular aspect of self-management, such as diet or exercise.

Measuring access

The success of level two education in meeting these objectives can be measured using information on the numbers and characteristics of people participating in level two initiatives.

Some of this data is easy to collect. Providers of group education and those who run face-to-face peer sessions tend to monitor the number of people accessing their services. Many collect demographic data enabling them to determine their success at engaging particular population groups, where these are being targeted. However, many of these measures require contextual information (for example, the size of the group being targeted) in order to be truly meaningful.

Some online approaches also enable the number of users to be monitored by requiring individuals to set up an account or register their details before they can access the relevant information. This also provides an opportunity to collect key data regarding the characteristics of those participating and the nature of their condition. In most of these cases it is also possible to track which sections of content individuals are accessing, how often, and for how long. As technology continues to advance, it is likely that the scope for collecting granular data will increase.

However, other online resources are open to anyone and therefore it is more difficult to understand their uptake. While it may be possible to determine the overall number of people participating in an online forum or viewing a web page, gathering more detailed information on these people's background or the nature of their condition is likely to be difficult.

Tracking the subsequent uptake of structured education courses, another objective of many level two programmes, can also be challenging. Although it might be possible to ask participants in a group session or at the end of an online course to indicate their intention to attend a structured education programme, determining whether or not this happens in practice is significantly more difficult.

Improving outcomes

All diabetes education aims to provide people with the knowledge and skills they need to manage their condition on a day-to-day basis. While level two initiatives do not offer the comprehensive education offered by structured courses, they do support this ambition by increasing and helping to maintain individuals' knowledge of key aspects of self-management, including any which are particularly relevant to their condition or lifestyle.

These initiatives also aim to help people to develop the skills and confidence they need to apply their knowledge and manage their condition effectively. This means engaging the individual in self-management activities, building up their confidence and empowering them to put these into practice successfully. Self-efficacy, the individual's beliefs about their ability to undertake certain actions, is an important concept within this context, and there is evidence that self-efficacy is a reliable predictor of behaviour change (Sturt *et al* 2010). Together with an increased knowledge of their condition, these should lead to changes in behaviour, and ultimately to a better quality of life. Outcomes such as empowerment, behaviour change and quality of life are sometimes described as 'psychosocial outcomes' (Steinsbekk 2012) and are often the primary focus of level two education initiatives.

Measuring outcomes

Measuring the outcomes of level two initiatives can be challenging. It is possible to track the overall effectiveness with which diabetes is managed using a number of clinical measures, such as glycaemic control. However, the inherently informal and infrequent nature of level two initiatives, often involving only a single session, means that in practice collecting this type of clinical data is difficult.

For example, the impact of an intervention on the individual's blood sugar levels may become evident in time, but it is unrealistic to expect that this information could be systematically or regularly collected from participants in the weeks or months following a one-off session, such as one of Diabetes UK's Living with Diabetes Days. Even where level two education takes place on a more regular basis, for example in the form of monthly peer interactions, the informal nature of these initiatives (which often involve little or no face-to-face contact) is likely to make the routine collection of clinical information impractical. A possible exception to this is online education, where users could be encouraged to assess themselves against a range of clinical indicators and record these in such a way that they are available to the education provider. However, an overarching challenge to the collection of clinical information in the context of level two education is the difficulty of isolating the impact of these initiatives from those produced by a range of other factors – such as clinical interventions, other forms of education and advice, and wider lifestyle factors.

Given these factors, it seems more appropriate to focus on the psychosocial outcomes associated with effective self-management, as described above. Measurement in most of these areas relies on individual reporting and is most valuable when information is collected before the intervention, to provide a baseline, as well as after. Increases in knowledge can be measured by asking participants about their levels of knowledge at the start of the intervention and then, once it has been completed, if they believe they have acquired new understanding. In the case of online education this could involve giving individuals the opportunity to test their understanding before and after going through the material. Increased confidence and a sense of self-efficacy can also be measured by asking individuals to report on how they feel before and after the particular intervention. In all cases, collecting information before, immediately after the intervention and also at a later date provides the best insight into outcomes. This applies in particular to changes in behaviour: while individuals can be asked to indicate how they plan to change their behaviour immediately after participating in education, asking individuals how they have changed their behaviour in practice six months or a year later provides a much better indication as to how long-lasting the outcomes are.

A review of the literature identified several tools that could be used to measure one or more of these psychosocial outcomes, such as:

- **Patient activation measure (PAM)** – a patient-reported measure comprising 13 statements designed to measure the extent of an individual's activation. In the management of long-term conditions, higher patient activation scores have been linked to better adherence to treatment and condition monitoring (Hibbard and Gilburt 2014).

- **Problem areas in diabetes (PAID) and the diabetes distress scale (DDS)** – both used to measure self-reported diabetes-related distress. Evidence suggests that PAID covers a wider range of emotional concerns (with greater focus on food-related issues), while the DDS is more reflective of distress relating to doctors' involvement in diabetes treatment and problems relating to diabetes self-management. However, both are considered to be helpful tools for measuring diabetes-related distress (Schmitt *et al* 2015).

- **Diabetes management self-efficacy scale (DMSES)** – used to measure perceived self-efficacy (the individual's belief in their ability or capability to undertake certain activities). It has also been shown to have strong validity for both clinical use and in research (Sturt *et al* 2010).

However, with any of these approaches it is important to note that, although patient-reported information is easier to collect than clinical outcomes, some of the practical barriers described above persist. This is particularly the case for online approaches involving a huge number of users, and where information is most usefully collected before, immediately after and a longer period after the intervention itself is complete.

A final outcome to consider in the context of level two (and indeed any) self-management education is user satisfaction. Again, this is a patient-reported outcome and relies on being able to collect information from participants at the appropriate point.

Outcomes of level two education

Overview

Overall, the evidence suggests that level two education initiatives can help to increase access to self-management education. Conversations with stakeholders demonstrated that where they are in place, locally developed approaches have been effective in attracting participants, including those who had not attended structured education courses. There is very little evidence on the ability of these programmes to appeal to users with a wider range of characteristics, particularly those with very low levels of patient activation.

However, it is important to note some of the limitations of the evidence, particularly in relation to outcomes. Few of the interventions described in stakeholder conversations involve the routine collection of outcomes data, and some of the evidence that is available is anecdotal. Where information on outcomes is provided, particularly where this is patient-reported, baseline information (comparative information on users prior to the intervention) was often not available. It is also important to note that for the most part, stakeholders were identified on the basis of their knowledge of or involvement in successful or well-developed initiatives.

Nonetheless, the literature provided some clear evidence on different aspects of level two approaches for diabetes and for other long-term conditions, offering some insight into the benefits of the approaches described earlier. The remainder of this section outlines the evidence available on the outcomes of the main approaches to level two education.

Face-to-face group-based approaches

There is good evidence that group-based self-management education for people with long-term conditions can improve knowledge and feelings of self-efficacy, and that it can lead to positive clinical outcomes. Some evidence suggests that education that is targeted at specific conditions is particularly effective. However, the literature also notes that some outcomes can diminish over time (National Voices 2014).

In the context of diabetes, many of the group-based initiatives that have been subject to formal study are similar to structured education in content and format. A number of these are also peer-based rather than professionally led approaches (discussed in the following section). Interestingly, however, there is some evidence that peer-based approaches that adopt a group format are more effective than those which take a one-to-one approach (Simmons *et al* 2015).

Formal evidence on access to and outcomes of level two type group-based approaches is relatively limited. In addition, some of the informal evidence is anecdotal and lacks baseline information. Nonetheless, conversations with stakeholders and less formal evidence indicated that group-based approaches are generally well attended, and that they can result in positive outcomes. For example, in 2015 Diabetes UK held 46 Living with Diabetes Days, which between them attracted nearly 3,500 attendees. CarbAware, a three-hour carbohydrate counting course in Berkshire for people with type 1 diabetes, is now experiencing a non-attendance rate of less than 20 per cent (non-attendance refers to those who accept a place on the course but do not attend) (Gallen 2015). The organisers of the two-hour Food and Diabetes Group in Lambeth also report high levels of attendance, and have noted that the course is particularly attractive to people for whom English is not their first language, although the course was not designed to target this group in particular. Those who run the course also believe that participants are more likely to attend a structured education course as a result of having attended the less formal session, although they currently do not have the data to confirm this.

Data on participants attending the CarbAware course demonstrated a reduction in HbA1c, as well as an increase in self-assessed confidence in all aspects of carbohydrate assessment and in intentions to increase monitoring (Gallen 2015). An evaluation of Diabetes UK's Living with Diabetes Days (LWDDs) identified a number of positive outcomes from the event, including a significant increase in participants' self-reported understanding of type 2 diabetes and an increase in their perceived confidence in managing their diabetes, including six and nine months later. The evaluation also found that following the event, four-fifths of attendees had improved their diet and half were exercising more, and that where people had been very successful at changing their behaviour this persisted six and nine months after the event (ICM Unlimited 2015).

Both the LWDDs and the CarbAware course (and the Lambeth Food and Diabetes Group) experienced high levels of participant satisfaction, with the vast majority rating LWDDs highly and indicating they would recommend them to a friend or relative.

Peer-based approaches

A review of the literature identified good evidence that peer-based approaches can have a positive effect on psychosocial outcomes, and that they are highly valued by participants. These factors, together with some limited evidence on access, suggest that peer-based approaches can play a valuable role in helping to increase the overall uptake of self-management education.

Early research on Diabetes UK's peer programme, Type 2 Together, found that the opportunities provided by a peer-based approach, such as social contact and the chance to 'normalise diabetes', were key drivers for attendance (although fear of others 'complaining' was cited as a reason for non-attendance) (Wright and Lamb 2015). A randomised controlled trial (RCT) comparing the impact of health advocate-led 'story-sharing' group sessions with nurse-led structured education found that the story-based sessions were better attended than the structured education course (Greenhalgh *et al* 2009).

In terms of outcomes, some studies suggest that peer-based approaches to diabetes education can result in improvements in clinical outcomes, such as a reduced HbA1c (Heisler *et al* 2010), or lower blood pressure (Simmons *et al* 2015). In general however, the evidence suggests that the primary benefits relate to psychosocial outcomes, such as quality of life and self-efficacy (Tang *et al* 2011). Research on a peer tutor programme in the Isle of Wight found that participants experienced an increase in wellbeing, self-care and adherence (Dix 2004), while a study into an eight-week peer-coaching scheme found that participants reported changes in their behaviour at the end of the programme (Joseph *et al* 2001).

There is also some evidence that peer-based programmes can achieve the same outcomes as those led by health care professionals. The RCT comparing health advocate-led 'story-sharing' group sessions with nurse-led structured education found no significant changes in outcomes in either group. The sole exception to this was a significant difference in the Patient Enablement Score suggesting that the story-telling approach left participants feeling better able to manage their condition (Greenhalgh *et al* 2009). A study into a peer adviser programme found that these individuals were as effective in delivering education programmes as health care professionals, and that they were acceptable to their peers as trainers in diabetes, provided they had had the necessary training (Baksi *et al* 2008). However, other evidence is mixed. For example, a review of self-management education programmes by lay leaders for people with a range of chronic conditions found that these could lead to a small, short-term improvement in two health behaviours (cognitive symptom management and exercise), and could increase self-efficacy, but found there were no significant effects compared with professionally led programmes (Foster *et al* 2007).

A clear message was that peer-based approaches are generally met with high levels of satisfaction from users. These approaches are seen to combine the benefits of receiving and providing social support (Heisler 2009), including in the context of peer tutor programmes where there is evidence that benefits are experienced not only by those in receipt of support but by those taking on the role of tutor (Dix 2004). The value that individuals place on engaging with people who share their condition comes across clearly even where peer support is not the primary focus for the intervention. For example, the 'opportunity for social comparison and support' was identified as one of the key attributes of Diabetes UK's Living with Diabetes Days (ICM Unlimited 2015).

There is some evidence that peer approaches that are group-based are more effective than those based on one-to-one interactions (Simmons *et al* 2015). Overall however, the evidence provides a consistent message that a range of peer-based approaches can bring about benefits, particularly in relation to psychosocial outcomes. These are accompanied by a high level of user satisfaction, suggesting that these approaches can play a key role in increasing uptake of self-management education.

Technology and internet-based approaches

Technology and internet-based approaches offer clear benefits in terms of increasing access to education; however, evidence on the outcomes of these approaches is more limited.

The internet in particular can be used to support a wide range of approaches to level two self-management education, from online information and courses to email-based peer support programmes and online discussion forums. The use of other forms of technology also facilitates increased access, for example, in the case of telephone-based peer programmes, or the use of phone apps as a source of information. In all cases a key benefit is the opportunity to make information accessible at any time to a huge population of people, thereby substantially increasing overall access to education. The online forum run by Diabetes.co.uk, for example, has more than 170,000 participants. These approaches generally provide users with a great deal of flexibility as to the content they access, and, for many people, they have the additional advantage of providing anonymity.

Evidence on the uptake of Mapmydiabetes and similar courses online is also helpful in this context. Mapmydiabetes is a QISMET-accredited provider that provides education that meets NICE guidelines, apart from the use of a face–to-face trained educator. While the content of these courses is more comprehensive than that provided by level two education initiatives, the numbers accessing education in this format (particularly when compared to structured education which is classroom-based) demonstrate the value of adopting an internet-based approach. Deployment data for Mapmydiabetes suggests that the number of people accessing this education is significantly higher than the numbers attending traditional, classroom-based structured education courses. Similarly, the Bournemouth Diabetes Learning Programme, which offers the structured education curriculum for people with type 1 diabetes in an interactive online format, now has approximately 36,000 registered users. This programme collects data on the length of time spent on the website (including on the individual modules) which demonstrates an average 'dwell time' of approximately 52 minutes.

In terms of outcomes, there is evidence in the literature that online approaches and telehealth in self-management education for a range of chronic conditions can improve knowledge, diet and physical activity, feelings of self-efficacy and, in some cases, clinical outcomes. For example, one study found that a mobile phone intervention led to statistically significant improvements in glycaemic control and self-management in people with diabetes (National Voices 2014). There is also evidence that telehealth can reduce the frequency of hospital admission for people with diabetes, chronic respiratory conditions and chronic heart failure (McLean *et al* 2013).

A study of an online version of the Expert Patient Programme for people with long-term conditions concluded that it could lead to decreases in symptoms and health care utilisation, and an improvement in health behaviours, self-efficacy and satisfaction with the health service (Lorig *et al* 2008).

Early evidence on Mapmydiabetes suggests that provision of a full curriculum in an online format has had a positive impact on clinical outcomes. As with each of the approaches described above, a number of the outcomes appear to be psychosocial, such as confidence, patient activation and behaviour change. A study conducted in 2001 that looked at different types of interactive technologies used in diabetes education concluded that in general these approaches were of moderate efficacy, with the greatest impact being behavioural change. The study's overall conclusion was that interactive technologies' greatest potential lay in their wide reach (Glasgow and Bull 2001). A survey of 791 users of internet discussion boards established by The Joslin Diabetes Center in Boston found that 74 per cent considered participation in the discussion board to have a positive effect on coping with diabetes and 71 per cent reported that it helped them to feel 'more hopeful' or 'a lot more hopeful' about coping with diabetes (Heisler 2009).

There is also evidence that these approaches are met with high levels of user satisfaction (as suggested by the high numbers accessing this type of education), and that in the context of peer-based approaches, telephone or email communication can be as acceptable to users as face-to-face contact (Heisler 2009).

Conclusions and areas for further study

Conclusions

A review of evidence in the literature and from conversations with stakeholders suggests that a variety of approaches to self-management education can be – and are being – used in addition to structured education. These range from online resources with a potentially infinite reach, to local schemes developed to meet the particular needs of the local population. Overall however, the picture is varied, with ad hoc approaches being developed to meet specific needs, rather than on a consistent basis.

Unfortunately, formal evidence on level two approaches is limited, and much of the informal evidence available comes from those who are aware of or involved in successful initiatives. In addition, baseline information is often unavailable. Nonetheless, it appears that where group-based learning, peer support and online approaches are in place these have been successful in attracting users. Despite the challenge of measuring the impact of these approaches, they also appear to be linked to positive outcomes, including increased knowledge and particularly in terms of patient engagement and self-efficacy. This is supported by some evidence in the literature on both diabetes self-management education and education for people with other chronic conditions.

In principle there is nothing to prevent any of the initiatives described in this report from being replicated in other areas, with equal success. Increasing opportunities for commissioners and education providers to share their experiences and learn from individual projects could help to encourage this. It is also worth re-emphasising the need for better signposting to the full range of education opportunities, as highlighted by the APPG for Diabetes (APPG for Diabetes 2015).

However, while each of the level two initiatives discussed play a valuable role in self-management education, a clear message from both the literature and from conversations with stakeholders was that people with diabetes are best served by having a menu of education options to choose from. This message is consistent with evidence collected by the APPG and others on what patients want. Having a mix of education options allows individuals to identify those that are best suited to their needs, lifestyle and learning style. Within this context it is also important to recognise that some people are less engaged in their health than others and may choose not to participate in many different forms of self-management education, even where there is a range of options. Information on the characteristics of those accessing education should be used to help to understand its effectiveness and to inform the development and expansion of new approaches.

Further study

This paper provides an initial insight into the different approaches being used in level two self-management education. However, cataloguing the initiatives taking place in the United Kingdom (and elsewhere) more systematically would help to provide a more comprehensive picture of the different formats this education can take, and how they can be best designed to meet the needs of particular population groups. Initiatives should also seek to capture the characteristics of their users to understand which groups are accessing education. Further research into informal approaches to self-management education for people with other long-term conditions, such as asthma, heart disease and epilepsy would also be beneficial.

As discussed throughout this paper, formal evidence on the outcomes of level two education in diabetes is currently limited. It is clear that all of the approaches considered in this paper can help to increase access to education and are associated with positive outcomes. However, more detailed outcomes information is important to help to focus future efforts to expand the self-management education offer.

There is some research under way currently that will provide some additional insight in this area. Diabetes UK has received government funding to pilot a Type 2 Together scheme. This is based on the 12-month RCT to assess the effect of peer support on metabolic control (involving 1,200 people with type 2 diabetes across Cambridgeshire and neighbouring counties) (Simmons *et al* 2015). Results of an evaluation of the pilot are due in spring 2016. There is also a HeLP-Diabetes RCT taking place to determine the effects of interactive internet-based intervention compared with a standard information website on self-management skills in people with type 2 diabetes. A study under way across Southwark and Lambeth in London to better understand the barriers to the uptake of the DAFNE course may also provide some relevant lessons for level two education.

Finally, further work is needed to determine the outcomes of the range of different level two approaches in diabetes self-management education, particularly over the longer term. Bearing in mind the practical challenges to systematically collecting information on clinical outcomes, a first step might be to determine whether any of the frameworks discussed in this paper would be appropriate for collecting baseline and outcome information on a more regular basis.

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