Peer support: more than tea and sympathy

For 30 years, peer support programmes have offered people with diabetes and other chronic diseases much more than tea and sympathy, adding value to professional advice. However, as Mark Greener here reports, patients’ ability to access peer support depends on where they live and there is a risk that services will jump too readily on the online bandwagon.

Peer support programmes for chronic diseases have been around for more than 30 years, beginning with pioneering work in arthritis. And it’s clear that peer support adds value to professional advice by focusing on often medically prosaic but practically important issues. In addition, peer support helps tackle the paucity of health care professionals (HCPs) available to support the growing numbers of people with type 1 (T1D) and type 2 diabetes (T2D).

Different approaches

Broadly, peer support takes one of three approaches: local face-to-face groups, phone support and online communities. Diabetes UK, for instance, holds peer support groups for T2D patients in local community centres across the country. The GP or diabetes nurse informs patients about the groups.

Deirdre Kehoe, head of service delivery at Diabetes UK, stresses the importance of ‘stringent’ recruitment and training of peer support ‘facilitators’. ‘We don’t want to suggest that the facilitator has expert advice to impart or that they are there to lead the meeting,’ she explains. ‘Their role is to ensure everyone’s voice is heard, to create a “safe” environment for people to speak, and make sure that everyone is “equal”.

Essentially, peer support aims to create a sense of community. ‘We run children and family events for people with T1D,’ Deirdre says. ‘Sometimes this is the first time that a child with T1D has met someone else with the condition or the parents have talked to another family facing the same issues.’

‘Group sessions help patients realise they are not alone with specific problems or challenges that they face on a daily and long-term basis,’ agrees Jacqui Charlton, Lecturer and Specialist Nurse in Diabetes, Edinburgh Napier University and NHS Lothian. ‘I do not get involved with patients pairing-up to communicate after sessions – but they often do.’

Dialling up

Phone-based programmes offer an alternative to peer support groups. A team based out of the Norfolk and Norwich University Hospital and University of East Anglia developed a phone-based approach that pairs ‘mentors’ with T2D to a person with pre-diabetes based on age, sex and interests. The Diabetes Prevention Mentors in our study are predominantly white, reflecting the local ethnicity mix for individuals with pre-diabetes and T2D,’ says Nikki Murray, Senior Research Associate on behalf of the Norfolk Diabetes Prevention Study, Norfolk and Norwich University Hospitals NHS Foundation Trust. ‘The average age of diagnosis of someone with T2D in Norfolk is 63 years. The average age of our current mentors is 62 years. In our study, everyone communicated in English, which again reflected our community. The principles of matching the participant and the mentor would, however, be remarkably easy to transfer and generalise to all ethnicities.’

Mentors phoned people with pre-diabetes, initially every four weeks for three months and then every eight weeks, to offer support and motivation regarding nutrition and physical activity that strengthened messages delivered by professional facilitators. The mentors also aimed to enhance the person’s self-efficacy, facilitating goal planning, self-monitoring using diaries and behavioural change. ‘A telephone-based service offers many advantages over a face-to-face service, most importantly the ability to make multiple attempts to reach the person relatively easily,’ Nikki comments. ‘A telephone-based approach is especially efficient in rural areas. Norfolk is approximately 75 miles east to west and in the time needed to travel to a face-to-face meeting, a mentor could make numerous successful contacts by telephone. This may differ in an urban setting where participants and mentors would be naturally closer.’

In addition, Nikki comments, telephone-based services can reach people with social difficulties, individuals who are carers or have dependants, and where cost of travel is a factor. In addition, many East Anglian communities remain remarkably tight knit. ‘A telephone-based service provides anonymity that even a private one-to-one, face-to-face consultation cannot,’ Nikki adds. ‘Telephone-based approaches allow individuals to keep that part of their life private.’

Importantly, mentors benefit from taking part. ‘Mentors reported improved diabetes management through lifestyle change, including increases in step count, cardiovascular exercise and dietary changes,’ Nikki comments. ‘Mentors employ a “practice what you preach attitude”, which provides a form of internal motivation. Mentors also reported friendship and support from peers, the ability to apply their listening skills to other areas of their lives and feeling like they are playing their part in giving back to the NHS, which was an important factor when deciding to express an interest in the role. They have a real sense that they have unique experience that could help others. This increases mentors’ self-efficacy, and feeling part of a worthy team and the project boosts their self-worth.’

Over the last seven years of recruiting, training and managing mentors, Nikki has learnt the importance of having a dedicated key worker as a point of contact and ‘a genuine caring interest in each mentor’. ‘It is vital to treat each mentor as an individual investing time and interest to build working relationships, rapport and trust,’ she says. The Norfolk Diabetes Prevention Study developed a specific training programme based on a full training needs assessment of each volunteer. The programme includes group-based, one-to-one training and ‘practice’ calls. Nevertheless, Nikki plans further studies to ascertain ‘what makes a great mentor’.

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‘We must discover the key skills and traits from those most successful mentors and incorporate these into training programmes,’ Nikki remarks. ‘What is it about mentors that participants value? Is it the shared experience? Is it the attitude that comes with the desire to help? Is it that someone is taking my diabetes risk seriously? In addition, we need to assess the impact of mentoring on diabetic markers.’

Diabetes UK, however, admits that they had less success over the three years they offered a peer support phone service. ‘We ran a telephone service staffed by volunteers with diabetes, but it was only available for 3 hours each evening and 95% of people calling during the day wanted to speak to someone immediately,’ Deirdre says. ‘So, we established a system where callers were asked if they would like to speak to one of our trained counsellors on our helpline instead – most said they did. We found that the peer support phone line was not especially successful, probably because the service was a reactive one rather than one where our volunteers had caseloads and proactively contacted peers, which is a much more resource intensive approach.’

And that points to the fundamental difference between the Norfolk study and the Diabetes UK service.

Surfing for support
The biggest challenge – as with structured education – is to get people with diabetes to engage with peer support. ‘Some come to a group once and feel it’s just not for them,’ Deirdre remarks. ‘But others who are initially sceptical come back time and again.’ Diabetes UK suggests setting a duration for the peer support, such as over a year or for monthly sessions. ‘This offers some people reassurance that they are not making an open-ended commitment,’ she says.

Furthermore, at the end of each session, the facilitator agrees a topic for discussion at the next meeting. ‘This shows that the session will offer more than “tea and sympathy”,’ Deirdre notes. ‘It shows that the sessions are relevant to their needs and focus on practical topics, such as travelling, taking care of your feet or eating well during holidays, such as Christmas and Ramadan. People with diabetes need to see it has value.’

Online communities can reach people who won’t or cannot engage with face-to-face or telephone support. Diabetes UK runs a very successful online forum. ‘People on a forum tend to be very engaged,’ Deirdre notes. ‘The online audience tends to be different from that attending the meetings.’ The charity is now looking at ways to bolster their online peer support.

However, offering a similar system on the NHS could present problems. ‘I would be anxious about developing an initiative where patients could communicate online that was endorsed by the NHS,’ Jacqui remarks. ‘I would want to check the correspondence to make sure it was accurate and up-to-date. Very often patients self-manage diabetes in a way that professionals would never recommend and people can misinterpret text. In a face-to-face group, professionals can rectify any misconceptions or incorrect advice. This is difficult and can be very time consuming online.’

Nevertheless, online support might be appropriate in certain circumstances. Jacqui is part of a group considering linking people who participated in face-to-face online education about insulin pumps. ‘This would probably need to be overseen by the HCP who put the group together,’ she says. ‘I also inform patients about several Facebook and Twitter groups that patients set up and lead.’

There is, however, a risk that online peer support could become a tick-box exercise. ‘As diabetes clinics are overstretched with the increasing prevalence of diabetes and NHS cuts, online initiatives could save time,’ Jacqui says. ‘However, if done correctly, developing online support takes a lot of time to develop, implement, evaluate and run. Online initiatives are the way forward, and are a “hot topic” in diabetes. So, it would be easy to jump on the bandwagon if HCPs were not aware of the disadvantages and problems that can occur.’

Fragmented funding
Peer support is diverse partly because of geographical and audience differences. But it’s also fragmented because of a lack of data showing that peer support is clinically and cost effective. Diabetes UK surveyed clinical commissioning groups (CCGs) and found that many are waiting for more robust data before commissioning peer support. It might be a long wait.

‘Proving cause and effect is difficult,’ Deirdre remarks. ‘We don’t have the data to show the extent to which, for example, a fall in blood pressure or HbA1c is due to peer support itself and how much reflects, for example, diet changes. In addition, the long-term nature of diabetes-related complications hinders analysis of the cost and clinical benefits of peer support.’

In the Norfolk Diabetes Prevention Study, recruitment and training cost £373 and £270 respectively per trainee. Ongoing running costs were predicted to be low.2 ‘Any heavily resourced programme offering one-to-one support must be certain it can be sustained in the current environment,’ Nikki remarks. ‘A telephone-based service still has substantial associated costs and should not be seen by commissioners or other parties as an easy or cheaper option. Volunteers are internally motivated. So, the time spent in individual relationship building and support could be more substantial than that needed for paid employees. Costs cannot, however, be exchanged for experience. The focus of any peer service should be a genuine desire to help others and share experiences. That is not something you can teach.’

‘Over the next five years and despite the lack of data, I believe that an increasing number of CCGs will see peer-to-peer support as an important part of diabetes services,’ Deirdre concludes. ‘However, we need better data to engage those CCGs that are currently disengaged. We also need to engage with HCPs to encourage more referrals to peer support. But some of the benefits can’t be captured in hard clinical or economic data. I’ve been privileged to spend time with families of children with T1D when they attend the peer-to-peer events as they realise they’re not alone. You can see the transformation in front of your eyes.’

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References
References are available in Practical Diabetes online at www.practicaldiabetes.com.
References