

Peer support: time to tap the (largely) untapped

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Introduction

Janet Kinson was responsible for the development of the original educational programme for diabetes specialist nurses in the UK.¹ Diabetes specialist nurses have now become core and crucial members of the team that educates and delivers care to those with diabetes. The presence of the diabetes specialist nurse is associated with diverse outcomes from reductions in length of stay among inpatients² to reductions in HbA_{1c} among ambulatory patients.³ However, patients who are ambulatory are generally away from health professionals for 8760 hours of their lives each year,⁴ and it is during this time that they can struggle with the daily demands of diabetes including lifestyle choices, medications, glucose monitoring and the emotional impact of a life and quality of life limiting condition. It is during this time, and even perhaps during the encounter with a health care professional, that a person with diabetes may need reassurance and support for their physical and mental well-being. From the UK to around the world, organisations (generally members of the International

Summary

There is growing evidence that the physical and mental health of people with, or at risk of, diabetes can benefit from support from a person with diabetes: known as diabetes peer support. Peer support involves the social and emotional help that supplements the assistance provided by health professionals and others in the life of the person with diabetes. By sharing, discussing, finding and facilitating the ways that can improve diabetes and overcome barriers to care and self-care, metabolic control and wellbeing can improve. Linking peer support to clinical care is thought to strengthen its effectiveness. Peer support complements diabetes education and facilitates implementation of the knowledge gained.

There are a range of different ways in which peer support can be provided. Peer support might arise from a casual discussion with another person with diabetes or within a more structured programme. The degree of training can vary from life with diabetes in the casual encounter, to group leadership, to paraprofessional training including motivational interviewing and a range of educational and management skills. The media for delivery varies from face-to-face, telephone and online approaches.

At a time of a growing diabetes epidemic, peer support could well be a key strategy in supporting those with and at risk of diabetes, reducing downstream demands on health services while improving quality of life. If this turns out to be the case, every neighbourhood, village and clinic should have one or more peer coaches to support diabetes prevention and diabetes management.

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Key words

peer support; barriers; diabetes; mental health; quality of life

Diabetes Federation) exist to promote the support that can be gained when one person with diabetes shares their situation with another person with diabetes. This 'peer support' probably happens even more often outside the organisations, and appears to be a natural event among humans in relation to a broad range of conditions (for example, cancer⁵).

Different forms of peer support

There are many ways by which peer support can be provided,⁶ and there appear to be two dimensions that define a peer support intervention as shown in Figure 1:⁷ the nature of the peer support (ranging between indifference to direction) and the nature of the relationship (from companion as would happen naturally [e.g. on a park bench] to paraprofessional, where the individual has an explicit health service role, e.g. peer advisors in the Isle of Wight).⁸

The questions that come to the fore are: 'Does peer support make a difference to the person, to their diabetes and to health services?' and 'Is there a potential for peer support to help us deal with the diabetes epidemic?'

My own involvement in peer support commenced in Coventry in 1986 while I was establishing the Coventry Diabetes Study (CDS), one of the largest diabetes epidemiological studies to occur in the UK.^{9,10} This household survey of the prevalence of diagnosed and undiagnosed diabetes among 10 304 residents of the electoral ward of Foleshill had a high response rate, particularly among South Asians (86%). The survey also compared the prevalence of diabetes among different South Asian groups¹¹ and the metabolic characteristics among Europids and South Asians.¹² However, prior to commencing the study, discussions

with the local city council Ethnic Minority Development Unit (EMDU) highlighted the importance of providing some public health benefits to the community, many of whom were of low socio-economic status and/or from a minority group. It was agreed that there would be a leaflet campaign to increase the awareness of diabetes overall¹³ and, to assist those with diabetes, the first South Asian Diabetes Support Group was to be established.¹⁴ A steering group was set up by a member of the EMDU with CDS support and the first meeting was held in 1987. All South Asians with known diabetes in Foleshill were invited. Attendance was 15–50. Meetings were largely held in Punjabi. The purpose of the group was: (i) to educate through invited speakers, videos and discussion; (ii) to provide mutual support; (iii) to share information relating to diabetes; and (iv) to form the basis of a social group. An evaluation in 1989 among the first 50 with very poor glucose control (HbA_{1c} 9.5% [80mmol/mol]) found that the HbA_{1c} dropped by 1.4% (15mmol/mol) among those who attended the group 2+ times but increased by 0.4% (4mmol/mol) among those attending 0–1 times. Similarly, diabetes knowledge increased more among 2+ attenders as assessed by a validated questionnaire.¹⁵ Although this was not a randomised controlled trial (RCT) and the cohort described had particularly poor glycaemic control, it provided a hint that peer support might be of clinical benefit. Since this time I have been looking at different ways in which to build on the support that peers can give and this has culminated in RCTs, one of which is currently underway.

On moving to New Zealand, the importance of diabetes as a public health menace was clear but, again, there were gaps in epidemiological knowledge, particularly in relation

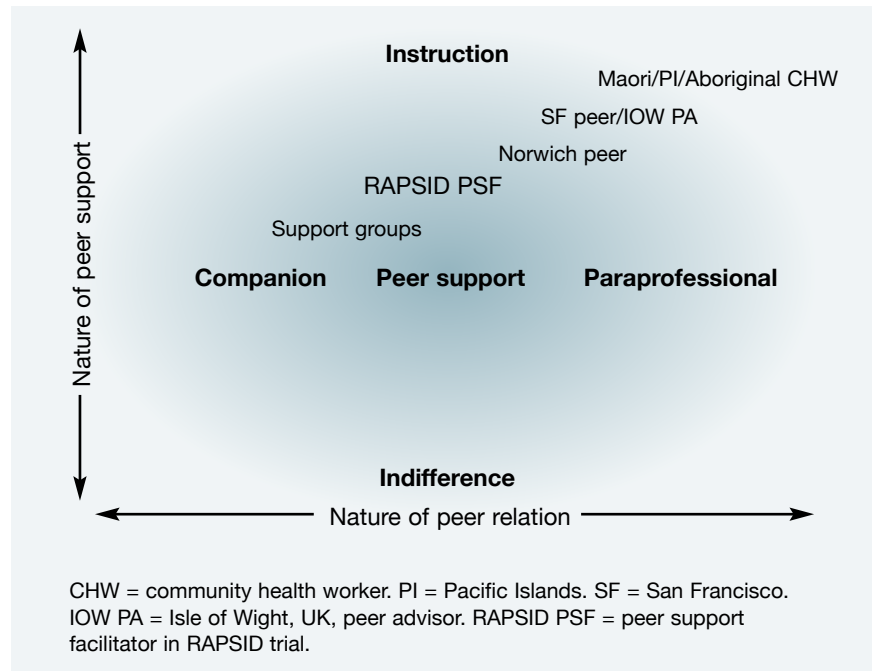


Figure 1. What is peer support? The 2 dimensions (adapted from: Simmons D, *et al. Diabetes Management* 2013;3:61–70).⁷ Also shown are the relative locations of different peer support interventions

to the prevalence of diabetes among Maori and Pacific people. As with Foleshill, there was a clear requirement to link any epidemiological work with interventions to prevent the harm that diabetes was causing.¹⁶ As a result, the South Auckland Diabetes Project (SADP, now the Diabetes Projects Trust www.dpt.org.nz/) was founded in 1992 to initiate a range of surveys and evaluated interventions.

A household survey was undertaken by specially trained local, previously long-term unemployed, people. Besides generating a detailed epidemiological picture of diabetes in this population,¹⁷ a framework was created describing barriers to diabetes self-care¹⁸ and the data informed a local diabetes plan.¹⁹ Within the local plan, was the recommendation to create a range of diabetes support groups that would be of use to Maori and Pacific people whose participation in the main diabetes support organisation, Diabetes New Zealand, was

limited at that time.^{20,21} A qualitative evaluation identified that group survival depended upon maintenance of a critical size of the group (at least >5) and that leadership and self-determination of the group (i.e. leadership by people with diabetes, rather than health professionals) were important.²⁰

At the same time, many of the previously unemployed field workers who had undertaken the household survey were trained to use the experience gained from interviewing those with diabetes to become lay diabetes educators.²² The role was designed for those without prior qualifications and particularly those who were long-term unemployed.²²

Working as peers, but also as paraprofessionals, the role was created to be able to help implement a local community based diabetes prevention programme and to support the Diabetes Education services. The purpose was to have individuals delivering the interventions who had similar backgrounds to the local

high risk communities, many of whom had limited formal education and/or spoke limited English. A further purpose was to assist the individuals themselves (who had been previously long-term unemployed) into the workforce. In all, two cohorts of these lay educators were established, a quarter of whom had diabetes and could therefore use their experiences to communicate the risks from diabetes.

Overall, in 1992/3, 31 students were trained and, by 1996, a follow-up survey was able to trace 19 of them: three were still working as community diabetes educators, three had used their training and experience to become nurses, one had used the polytechnic qualification to enter and complete an accountancy degree, nine were in other employment and only three were still unemployed. A further 10 were lost to follow up and two had died.

The lay educators delivered a diabetes prevention intervention that included awareness sessions, lifestyle education, a video,²³ cooking demonstrations, a within-church exercise programme (and promotion of e.g. gym attendance) and other supporting activities.²⁴ This was commenced in an RCT, randomising two Tongan and two Western Samoan church congregations to either intervention or control.

In the Western Samoan intervention church, the lay educator became the church health leader and participation in the programme was much higher. This followed through such that in the Western Samoan, but not the Tongan, intervention church, the lay educator led programme was associated with significant reductions in weight gain, waist circumference and increases in exercise.

In both churches, there was an increase in diabetes knowledge, but

this was greater in the Western Samoan congregation. The Western Samoan intervention church also experienced a shift in the number of people maintaining lifestyle change.

This RCT clearly showed the ability of lay educators to intervene to support lifestyle change and attitudes, but that this required careful organisation and local leadership, otherwise change could be limited as shown in the Tongan church.

The next model of lay or peer support in which I was involved was with an Aboriginal health worker in Victoria, Australia. Within the Aboriginal health service, we established a diabetes specialist clinic alongside the primary care team which included the Aboriginal health worker.²⁵ Patients who attended were those with an HbA_{1c} of $\geq 9\%$ (75mmol/mol), type 1 diabetes and nephropathy. This approach, among those at the highest risk of diabetes complications, was associated with high attendance at the retinal screening (96.7%), high levels of self blood glucose monitoring (90%), improvements in HbA_{1c} (10.4% down to 7.9%), blood pressure (138/78 to 127/73mmHg) and total cholesterol (6.0 to 5.0mmol/L).²⁵ The Aboriginal health worker had a vital role between clinics, supporting those with diabetes and also during the clinic, when she would support those waiting or seeing the health professional. She primed health professionals before they saw a patient, advising of any recent experiences that could have impacted on self-care, or could increase the sensitivity of the patient during discussions about what had or had not been able to be achieved since the previous clinic.

Returning to New Zealand provided the opportunity to establish an RCT of the efficacy of the delivery of a diabetes prevention intervention among Maori by Maori community

health workers (MCHWs) – Te Wai o Rona: Diabetes Prevention Strategy.²⁶ This involved the development of a lifestyle programme by those with varied backgrounds, often with diabetes themselves or in their family, those who lived either in the town or rurally or by the sea or inland, Maori with a range of past education experiences – but all having a high risk of diabetes. The RCT was organised with Maori involved at every stage and leading the intervention in their area. The RCT was funded with both research and service funding with objectives to recruit 5000 Maori family members into the study and to demonstrate a reduction in new cases of diabetes by 35% over three years at a cost *per capita* of NZ\$200.

The intervention adapted the learning from the SADP work and included the MCHWs, who were from the local community, providing the intervention using a structured and monitored approach. The aim was for the initial knowledge and skill acquisition and motivation to come from the MCHW through a structured approach to both healthy eating and physical activity, but then that lifestyle maintenance would be increasingly supported by others in the community: MCHW input (and therefore cost) would decline. As the MCHW was from the local community, they would still be in a position to maintain community interest and return to those whose activities were waning.

A six-month pilot among the first 155 participants (compared with 29 well-matched participants who started later) showed the acceptability and utility of the toolkit and lifestyle messages (www.sportwaikato.org.nz/key_messages.cfm). The intervention was associated with a 5.3kg weight loss among those with impaired glucose tolerance/impaired fasting glucose (IGT/IFG) and 1.3kg weight reduction among

those with 'normal' glucose tolerance. As the recruitment of the 5000 participants took longer than planned for a range of operational reasons, further funding was required and the research funding was not able to be obtained: sadly, the full roll out did not proceed.²⁷ However, an RCT where people with diabetes provide the support for diabetes prevention through lifestyle change among those with IGT/IFG is currently underway in Norfolk and the findings will assess the efficacy of lay people/peers delivering diabetes prevention.²⁸

In November 2007, the World Health Organisation arranged a consultation over peer support.²⁹ The format included workshops and, particularly, discussion dissecting out the difference between peer support and peer education; again, Figure 1 shows where these different activities rest in the continuum between companionship and being paraprofessional.

The key functions of peer support were defined as:

- Assistance, consultation in applying management plans in daily life.
- Social and emotional support.
- Linkage to clinical care.

This support was seen as ongoing, extended over time, but could well be intermittent depending on the need of the person with diabetes and their wider commitments. Attending the meeting were representatives from an organisation called Peers for Progress (<http://peersforprogress.org/>).

Evidence for peer support

One of the key gaps identified in the peer support literature was well-performed RCTs of peer support. Peers for Progress put out a Request for Proposals to fund eight RCTs and six 'demonstration' projects to obtain evidence about the efficacy and effectiveness of peer support in different

	1:1 Peer support	
Group-based support	Control	1:1 only
	Group only	Both

Figure 2. Study design of the RANdomised controlled trial of Peer Support In type 2 Diabetes (RAPSID)

settings.³⁰ One of the RCTs has already published its findings.

The model enrolled 299 low income patients, with an HbA_{1c} ≥8% (64mmol/mol) from public health clinics in San Francisco and randomised them either to a peer coach who worked as part of the primary care team, or as controls. They trained 23 patients with an HbA_{1c} <8.5% (69mmol/mol) over 36 hours. After six months, the HbA_{1c} had decreased by 1.07% in the coached group and 0.3% in the usual care group (p=0.01). This translated into a drop in HbA_{1c} of 11mmol/mol (1%) or more in 49.6% coached patients, but in 31.5% of those under usual care.³¹

A recent meta-analysis³² identified 569 papers relating to specific peer support programmes for those with diabetes, of which 25 were considered adequate to enter into a meta-analysis including 10 RCTs and four randomised comparative trials. The diversity of peer support was shown through eight being almost entirely group face to face, three also included telephone support, one was by telephone support alone, and two were internet based. There were varying degrees of training, supervision and a range of content from the educational (e.g. foot care) to ways to facilitate self-management (e.g. goal setting) and emotional and social support.

Metabolic benefits were shown only in a minority of RCTs (HbA_{1c} [n=3], blood pressure [n=1], cholesterol [n=1], weight [n=2]). Different health behaviour (e.g. lifestyle, glucose monitoring, medication use), empowerment (e.g. self-efficacy, perceived barriers, knowledge) and psychological (e.g. depression, diabetes distress) outcomes were used, and, again, a minority of trials showed a benefit. While many of the trials would appear too small to detect a difference, the evidence remains variable whether peer support is of clinical benefit, although much depends on the approach used and the fidelity of the intervention.

Our own Peers for Progress trial is known as RAPSID: RANdomised controlled trial of Peer Support In type 2 Diabetes; the intervention and process have already been piloted³³ and the main trial is underway. The trial asks: 'Can peer support, delivered as a group and/or individual intervention, enable people with diabetes and improve their health?' It is a 2x2 factorial design as shown in Figure 2. One key component that builds on the New Zealand work was to incorporate a community context, to try to enhance the peer support (and minimise the chance of becoming bored with the content of the interactions only focusing on diabetes). To achieve this, RAPSID is a cluster RCT, with the cluster being defined by one or more parish council areas (i.e. villages). Where possible this was one village, but where numbers were too small, areas were combined. Participants are invited in largely through their general practice, although a community approach also occurred with posters, items in parish council newsletters and pharmacies, as well as mail-outs from Diabetes UK to its members and local diabetes services.

Participants will be assessed at baseline, 4–6 months and 8–12 months and the primary outcome is HbA_{1c}. Secondary outcomes are metabolic (blood pressure, lipids, weight), quality of life (EQ5D) and psychological (depression, self-efficacy, adherence and perceived barriers to self-care).

A recruitment target of 1200 was set to be able to detect small differences in HbA_{1c} and allow some loss to follow up over the time period. Over 1300 have actually been recruited. Participants volunteer to be a peer support facilitator, are then observed for suitability as they go through structured education (that is provided to all participants before the allocated peer support commences) and the peer support facilitator training, and are then allocated to their intervention and peers.

The intervention is at least monthly and peer support facilitators have to provide a report. Clinical support is provided by a RAPSID nurse who meets with the peer support facilitators, from each of the interventions (separately) on a monthly basis by geographical district (about 12 meetings each month). The intervention is standardised by function not content.³⁴ The peer support facilitators have been asked to: discuss barriers to care; find ways to assist in managing diabetes in daily life; provide social and emotional support; provide ongoing support during the trial; and link with clinical care through the RAPSID nurse.

The study protocol was adjusted following the two-month pilot³³ which was undertaken across four general practices. Overall, 21% responded with a barriers to diabetes care postal survey undertaken to identify reach (i.e. the characteristics of those in and outside the trial); 15% opted to be in the trial and, unlike in the main trial, peer

supporters (as they were then called) were selected by their general practice.

The main findings (besides that the trial was feasible and the processes were largely appropriate for the RCT) were that the peer supporter was put on a pedestal and had the potential to behave in a more paraprofessional than peer manner. To address this, their title was changed to 'peer support facilitator' and they were recruited from among the participants rather than by general practice recommendation. The other key issue was that the participants were hungry for diabetes education and this disrupted the peer support facilitator training. In view of this, the baseline education was put before the peer support facilitator training.

The future

If RAPSID and the other Peers for Progress RCTs confirm the utility of peer support, the next question is how it would be best implemented on a population basis. RAPSID is generating a picture of the cost of the intervention (e.g. venues, clinical support) and this would help with understanding its affordability. So far, the intervention has been at a lower cost than expected, as the peer support facilitators often meet in a low cost/free local community facility.

If peer support is seen as affordable and wanted (which it seems to be in every country in the world), then RAPSID and other trials should provide a range of approaches to peer support that can augment the current knowledge. Peers for Progress already has guides to setting up peer support (<http://peersforprogress.org/>) as do a variety of national organisations.

At a time of a growing diabetes epidemic, peer support could well be a key strategy in supporting those with diabetes to self-manage and cope with their diabetes better,

reducing downstream demands on health services while improving quality of life. If this is the case, then access and availability would be crucial. From our experience with RAPSID, we would suggest that every neighbourhood and village should have one or more peer coaches to support diabetes prevention – weight management, weight maintenance and physical activity – and should also have a peer support facilitator to support those with diabetes with assistance in managing diabetes in daily life, providing social and emotional support within a framework that links them to clinical care. The linkage should be put into place in a way such that every practice/service would include peers in their health care delivery model.

We shall see whether such a network is created. Even so, we do seem to be approaching a point where we will know better the extent of any benefits from peer support and how to facilitate its establishment: almost time to tap the largely untapped!

Declaration of interests

There are no conflicts of interest declared.

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