

The DAWN2™ (second Diabetes, Attitudes, Wishes and Needs) study: Relevance to the UK

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The recently published DAWN2™ (second Diabetes, Attitudes, Wishes and Needs study) is a landmark research study, which reports views and perception of adults with diabetes, family members of adults with diabetes, and healthcare professionals from 17 countries across four continents, including the UK. This review discusses the findings and implications of DAWN2 from both a global and UK perspective. It highlights the need to build upon the strengths of good healthcare provision and healthcare organisation for people with diabetes. The findings also highlight the need for a more person-centred approach and emphasise the importance of good family and societal support for people with diabetes.

Psychosocial issues are now considered an integral part of diabetes; these are concerns that have to be addressed while managing the condition. Yet, it was not always so.

We will soon be able to celebrate 100 years of insulin use, and the effect it has had on the lives of millions of people with diabetes cannot be overestimated. Other drugs, both oral and injectable, have also been developed to help manage diabetes. Along with novel drugs, we now use modern methods of diagnosis, monitoring and follow up. These innovations, along with attention to nutrition and physical activity, have helped improve the outcomes for people with diabetes. Yet, the biological or biomedical advances in diabetes care were not matched by equivalent improvement in psychosocial management. This was due, in part, to lack of evidence, although, pioneer nurses and clinicians had reported on the importance of emotions in glucose control, and the need to maintain emotional stability in diabetes (Meyer et al, 1945; Daniels, 1948). The advent of evidence-based medicine, however, meant that newer yardsticks of evidence began to be applied to psychosocial aspects of diabetes.

DAWN™ study

The DAWN (Diabetes, Attitudes, Wishes and Needs) study, was seminal in providing this evidence. Conducted in 2001, DAWN collected data to demonstrate the high burden of psychological and psychiatric morbidity on people with diabetes, inadequacy of diabetes care and self-management, limited access to psychological care, and lack of interdisciplinary team care (Peyrot et al, 2005). DAWN found that healthcare providers desired greater understanding of these aspects of diabetes care, and wished for collaborative management to improve outcomes (Peyrot et al, 2006).

The DAWN study led to a DAWN “Call to Action”, crafted by both people with diabetes and healthcare professionals, which encouraged implementation of interdisciplinary person-centred diabetes care. Various strategies were put forward to help achieve this overarching vision (Wroe, 2004).

Since the DAWN study was first reported, major improvements have taken place in the field of diabetes psychology. In the UK, for example, DSNs are considered an integral and equal part of the diabetes care team, although this status is under threat. It has

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Article points

1. DAWN2™ was a multinational investigation of people with diabetes, family members of individuals with diabetes, and healthcare professionals, to assess potential barriers to, and facilitators of, active and successful diabetes management.
2. The DAWN 2 study results serve to document the existing state of affairs and help inform feasible strategies to achieve the goal of person-centred diabetes care, with active support and communication between various stakeholders.
3. The key action areas that can make a difference to diabetes care include improved communication between people with diabetes, their family and healthcare professionals, improved awareness of the need for psychological and psychosocial care, and better access to education programmes.

Key words

- DAWN2
- Family support
- Healthcare professionals
- Patient-centred care

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Page points

1. NICE now has emphasised the importance of psychological aspects of diabetes care by including “assessment and management of psychological problems in people with diabetes” in a quality standard.
2. DAWN2™ is a multinational investigation of people with diabetes, family members of individuals with diabetes, and healthcare professionals, to assess potential barriers to, and facilitators of, active and successful diabetes management.
3. People with diabetes reported a significant burden of treatment (66.9% globally, 65.5% in the UK), with many reporting poor quality of life (13.4% globally, 16.3% in the UK) and possible depression (14.8% overall, 17.3% in the UK).

been suggested that the NHS is not recruiting enough DSNs to keep pace with the growing number of people diagnosed with diabetes, according to a recent report by Diabetes UK, the Royal College of Nursing (RCN) and TREND-UK (Diabetes UK, 2014). This is one of the important functions of DSNs, who not only provide much needed psychological support to people with diabetes, but also identify significant psychological issues that may impact diabetes control, and manage referral to mental healthcare professionals, if needed. NICE now also has emphasised the importance of psychological aspects of diabetes care by including “assessment and management of psychological problems in people with diabetes” in a quality standard (NICE, 2011).

DAWN2™ study

Following on from the DAWN study, no objective assessment of the status of psychosocial health in diabetes had been carried out for a decade. To fill this gap, the second DAWN study (DAWN2) was commissioned. Reported in 2013, DAWN2 is a multinational investigation of people with diabetes, family members of individuals with diabetes, and healthcare professionals, to assess potential barriers to, and facilitators of, active and successful diabetes management (Peyrot et al, 2013). DAWN2 surveyed 8596 adults with diabetes, 2057 adult family members of adults with diabetes, and 4785 providers of care to adults with diabetes. These were spread in 17 countries over four continents. Apart from the UK, other European countries included in DAWN2 were Denmark, France Germany, Italy, the Netherlands, Poland and Spain (Peyrot et al, 2013). The UK cohort of 281 healthcare professionals included 120 GPs, 81 specialists and 80 nurses/dietitians involved in the management of diabetes.

Burden of diabetes

People with diabetes reported a significant burden of treatment (66.9% globally, 65.5% in the UK), with many reporting poor quality of life (13.4% globally, 16.3% in the UK) and possible depression (14.8% overall, 17.3% in the UK). People with diabetes in the UK ranked 15th out of 17 in terms of quality of life, and 12th in likelihood of depression. Diabetes distress was relatively less common in the UK participants; only 19.2% reported high distress, compared to a global mean of 28% (Nicolucci et al, 2013).

Not surprisingly, the UK scored well in terms of minimal financial impact of diabetes as people with diabetes do not pay for their medication prescriptions in the UK. This includes blood glucose monitoring strips, oral and injectable therapies. Residents of the UK with diabetes had similar experiences to peers from other countries in terms of impact of diabetes on physical health, work or studies, and ability to live a normal life. They reported a greater impact on leisure activities (second highest impact) and relationship with family, friends and peers (fourth highest impact). These findings were corroborated by family members in UK, of whom 8% reported “poor/very poor quality of life”, and 10.2% reported likelihood of depression. The family members from UK reported a negative impact of diabetes on various facets of their life, in proportions similar to respondents from other countries (Kovacs Burns et al, 2013). Hypoglycaemia has a profound impact on people with diabetes and family members (Munro et al, 2014). A high proportion of GPs and specialists (78% and 91%, respectively) indicated that reducing the risk of hypoglycaemia was one of the improvements to currently available medications that would be most useful in helping people achieve better outcomes.

One interesting facet of the study highlighted that a large percentage of nurses/dietitians (44–60%) agreed it was important to understand the emotional issues faced by people with diabetes compared with 21–28% of GPs. This highlights the need for teams to work together with people with diabetes on how their care is managed (Holt et al, 2013).

Support from family

Whilst many family members in the UK reported good quality of life, diabetes was often linked to concerns for the future, particularly for those treated with insulin; however, it was also found that diabetes could have a positive effect on family members living with people with diabetes. UK results of DAWN2 stand out regarding family issues. Over half (54.5%) of family members mentioned that the person with diabetes informed them about his/her needs or asked for support (global result was 51.6%). A total of 38.5% family members in the UK (similar to the overall average of 38.7%) were willing to be more involved in diabetes care, and 46.6% (similar to global mean 45.6%) were willing to help people with diabetes deal with their feelings about the condition (Kovacs

Burns et al, 2013). The families in the UK reported a much lesser burden of helping the person they live with manage their diabetes; only 24.5% had a moderate-to-very large burden (fourth lowest out of 17 countries), compared to 33.7% globally. Yet, the UK had an average score on the “family support” scale (ninth out of 17), and 39.0% of family members reported frustration in not knowing how best to help the person with diabetes (global average was 36.7%; Kovacs Burns et al, 2013).

Family support

People in the UK with diabetes were less positive, however, in their opinions about their family members. Globally, 60.2% received support from persons most involved in diabetes care, while in UK, only 58.0% did so. The family was thought to be somewhat, or very, supportive by 82.2% of people with diabetes worldwide, but only by 56.0% in UK (ranked 16 out of 17). Equally, poor rankings were given by people in the UK with diabetes to their friends/people close to them (ranked 14), people at work/school (ranked 14) and others in their community (rank 17). Unfortunately, the least favourable remarks were reserved for the healthcare team. UK healthcare professionals were ranked last in terms of supportiveness, as assessed by people with

diabetes (64.3% versus global 84.6%; Nicolucci et al, 2013).

Self management and education

Self-management practices of UK people with diabetes were similar to those from other countries. They had followed a healthy-eating plan on 5.2 days; participated in at least half-an-hour of physical activity on 3.0 days; tested blood sugar on 3.7 days; self-checked their feet on 3.6 days; and adhered to medication schedule on 6.4 days during the preceding week. Participation in education programmes (72.5%) was better than the global experience (58.6%); with 79.4% reporting that the programmes they attended were helpful (Nicolucci et al, 2013). *Figure 1* shows the percentage of people with diabetes who had attended diabetes education programmes. However, only 20.9% of family members had participated in such events (global 22.3%), with 69.6% of family members reporting that these programmes were helpful (Kovacs Burns et al, 2013).

In the UK, structured education programmes are advocated for all but there is a disconnect between the percentage of people referred to these programmes and the number who attend. DAWN2 found that in the 12 months prior to the survey, only 14% of people with type 1 diabetes and 6% of people with type 2

Page points

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3. The DAWN2™ study showed that there is an apparent disconnect between what healthcare professionals believe and what people with diabetes believe in relation to diabetes care.

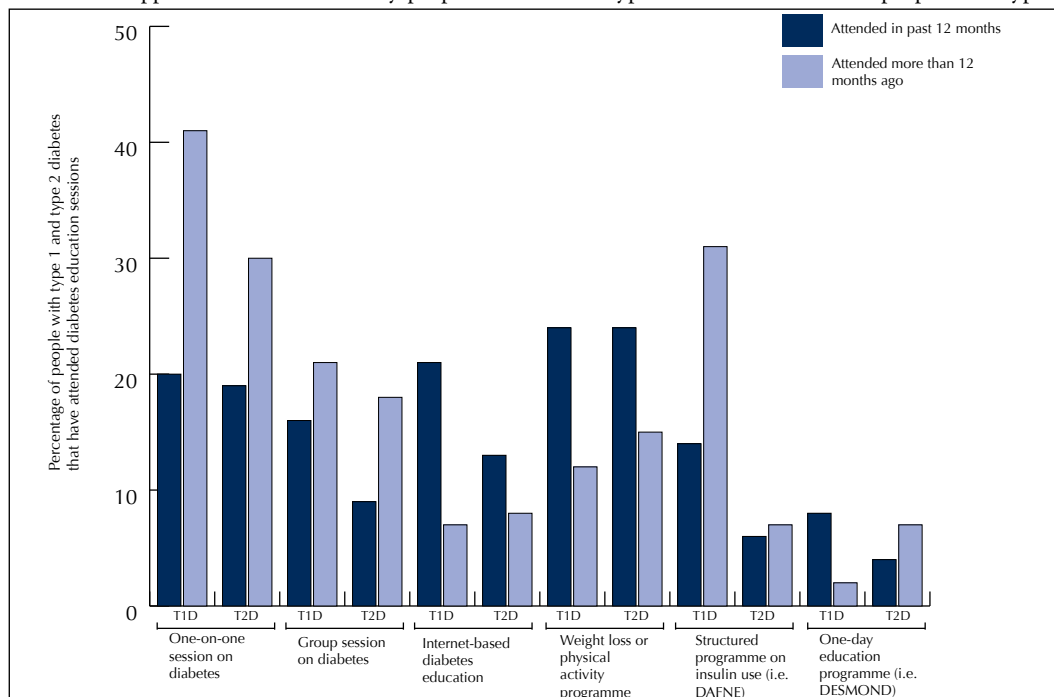


Figure 1. Percentage of people with diabetes who attended diabetes education, either in the past 12 months or more than 12 months ago (reproduced with permission from Davies et al, 2014).

Page points

1. The responses of UK healthcare professionals were similar to global results; however, a greater number of UK professionals thought it would be helpful if people with diabetes find information themselves on self-management.
2. A greater number of UK healthcare professionals had attended post-graduate training in medical management of diabetes (49.7%) than colleagues from any other country.
3. Access to diabetes education programmes by people with diabetes and family members in the UK is poor and requires improvement.

diabetes had attended a structured diabetes education programme. Perhaps this is not too surprising, with only 53% of GPs stating it needed improvement. It has been suggested that many people with diabetes rely on, and prefer, printed materials for their educational needs (Davies et al, 2014).

Quality of health care

The DAWN2 study showed an apparent disconnect between what healthcare professionals believe and what people with diabetes believe in relation to diabetes care. Nearly one in four people with diabetes (21–23%) responded that their healthcare professional “always/most of the time” asked them about problems with their medication or their effects, where in contrast, 65–85% of healthcare professionals indicated that they did (Nicolucci et al, 2013; Holt et al, 2013). Effective care planning is needed with goals and targets agreed between the person with diabetes, their family and healthcare professionals.

When the quality of healthcare provision was assessed through patient-reported indicators, surprisingly, a different picture emerged. UK people with diabetes reported, over the past 12 months, that their healthcare team had measured long-term blood glucose control in 78.4% of cases (global, 76.5%); examined their feet in 79.8% cases (best ranking country, global 52.8%); asked if they were anxious or depressed 42.8% of the time (ranking third, global 32.8%); and asked about food consumption 42.6% of the time (global 45.4%). Satisfaction regarding organisation of care was 59.9% in UK (fourth best), compared to 50.2% globally (Nicolucci et al, 2013).

Healthcare professionals' perspective

As part of DAWN2, UK health professionals reported their attitudes and practices relating to diabetes care. While most of the responses obtained from the UK were similar to global results, a few attitudes stand out. For example, a greater number of UK professionals thought it would be helpful if people with diabetes find information themselves on self-management (82.1% versus 72.0% globally, ranking fourth).

A lesser number felt that major improvement was needed in self-management in most of the areas queried, including blood glucose testing, dealing with diabetes-associated emotions, maintaining healthy weight, and taking responsibility for managing their condition. UK healthcare professionals were relatively

more satisfied with all areas of healthcare provision, as well as healthcare organisation, than their colleagues in other countries and fewer of them felt the need for major improvement in these areas. Sadly, it is possible that the *Quality and Outcomes Framework* has set funding targets for diabetes care in the UK that may not match what individuals with diabetes want, or are able to, achieve (NHS Employers, 2012). Focus on the individual, and inclusion in team decision making, is vital for successful outcomes.

A greater number of UK healthcare professionals had attended post-graduate training in medical management of diabetes (49.7%) and effective communication and motivation strategies to support long-term behaviour change (31.5%) than colleagues from other countries (global values were 64.5% and 29.3% respectively). Despite this, they ranked poorly on all indicators of person-centred chronic illness care (1. Healthcare Professional Patient Assessment of Chronic Illness Care, DAWN short form; 2. Healthcare Professional Health Care Climate, DAWN short form; 3. percentage of healthcare professionals asking how diabetes affects their patient's life), taking 14th, 15th and 16th place for the three indicators (Holt et al, 2013).

Societal discrimination

Discrimination in diabetes continues to exist. While 14.5% of people with diabetes living in the UK reported discrimination (global, 17.6%), this sentiment was shared by 20.1% of UK family members (global, 20.5%), and 15.1% of UK healthcare professionals (ranking second) also reported the need for major improvement in accepting people with diabetes as equal members of society, as opposed to the global average of 31.1% (Holt et al, 2013).

Conclusion

These DAWN 2 study results serve to document the existing state of affairs and help inform feasible strategies to achieve the goal of person-centred diabetes care, with active support and communication between various stakeholders. A helpful analogy is that DAWN 2 serves as a lighthouse – it describes our current situation, as well as providing a pathway to our goal. The UK has strong post-graduate training, healthcare provision and healthcare organisation to serve people with diabetes. Our healthcare professionals score well in most patient-reported

indicators. The low financial impact of diabetes is evidence for the adequacy of the current health system, although this could be offset by the paucity of structured education available.

Access to diabetes education programmes by people with diabetes and family members is poor and requires improvement. DAWN2 results show that those who managed to access an education programme found it useful. Much could be done to increase availability of these programmes and encouragement of people with diabetes to attend. If it were seen as part of the treatment package for diabetes, as it is in some other countries in the study, uptake would surely be improved.

A few areas that need improvement stand out. UK healthcare teams scored poorly on indices of person-centred care, and are rated poorly by people with diabetes for their supportive attitude. Consultation times are short and the healthcare team does set targets, but there is a great need to involve the individual in their own care with agreed goals within a care plan. While people with diabetes feel that their healthcare team members are not supportive enough, their team members feel that people with diabetes should search for information related to self-management on their own.

Beyond these antipodal patient-provider expectations, a similar communication gap exists between the person with diabetes on one hand, and the family and community support on the other. While people with diabetes reported that their family and colleagues do not do enough to support them, family members report lack of communication. People with diabetes often do not share their needs, and this leads to frustration in family members, as they do not understand how best to help their loved ones. This communication gap needs to be addressed.

One must not ignore the strong message, conveyed by people with diabetes, through the DAWN 2 study. People with diabetes in the UK are relatively satisfied with healthcare organisation and provision, and rate their healthcare providers favourably on individual, "biological-oriented" aspects of diabetes care. However, they strongly observe the lack of "support" from all sections of society, including the healthcare professional. The attitude of healthcare professionals, in wanting people with diabetes to search for self-management tools themselves further fuels this negative opinion reported by person with diabetes.

Call for action in the UK

Improvements can easily be made in the quality of diabetes care in the UK. The key action areas that can make a difference to diabetes care are:

- Improved communication between people with diabetes, their family and healthcare professionals.
- Improved awareness of the need for psychological and psychosocial care.
- Better access to, and uptake of, education programmes.
- Improved information available to all on prevention of hypoglycaemia.
- Involvement of the person with diabetes in how best to manage their condition.

In response to the DAWN2 UK findings a National Action Plan (NAP) has been developed to support the delivery of person-centred care (Novo Nordisk, 2014). The NAP in the UK will utilise innovative tools and resources to improve the key action areas above. The DAWN2 study should herald an era of enhanced person-centred care for people with diabetes, leading to better glycaemic control and quality of life. The UK NAP should serve as a best practice worthy of emulation across the globe. ■

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