

A new DAWN: Improving the psychosocial management of diabetes

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ABSTRACT

Aims: The second Diabetes Attitudes, Wishes and Needs (DAWN-2) study assessed psychosocial issues and health-care provision of people with diabetes, their family members and health-care professionals. **Materials and Methods:** Participants completed an online, telephone or in-person survey designed to assess health-related quality-of-life, self-management, attitudes/beliefs, social support and priorities for improving diabetes care as well as health-care provision and the impact of diabetes on family life. **Results:** A total of 8596 adults with diabetes, 2057 family members of people with diabetes and 4785 health-care professionals across 17 countries completed the survey. There were significant between country differences, but no one country's outcomes were consistently better or worse than others. A high proportion of people with diabetes reported likely depression (13.8%) and poor quality-of-life (12.2%). Diabetes had a negative impact on many aspects of life, including relationships with family/friends and physical health. A third of family members did not know how to help the person with diabetes, but wanted to be more involved in their care. Many health-care professionals indicated that major improvements were needed across a range of areas including health-care organization, resources for diabetes prevention, earlier diagnosis and treatment and psychological support. **Conclusions:** DAWN-2 is a multinational, multidisciplinary systematic study that compared unmet needs of people with diabetes and those who care for them in 17 countries across four continents. Its findings should facilitate innovative efforts to improve self-management and psychosocial support in diabetes, with the aim of reducing the burden of disease. The implications for India are discussed.

Key words: Diabetes, family, India, person centered care, psychosocial

INTRODUCTION

Despite advances in therapies and health-care and increasingly sophisticated guidelines, sub-optimal diabetes control remains the norm in many countries with adverse consequences for the individual with diabetes and burgeoning costs for the wider health economy.^[1] Over the last few years, a greater understanding of the non-medical factors contributing to poor diabetes management have

led to calls to move away from a purely medical model toward a greater emphasis on the psychosocial aspects of diabetes.^[2]

In 2001, the Diabetes, Attitudes, Wishes and Needs (DAWN) study,^[3] undertaken in 13 high-middle-and low income countries, found that both people with diabetes and their health-care professionals reported that there was insufficient care and support to meet the psychological and educational needs of people with diabetes. The study highlighted the importance of a multidisciplinary team of health-care professionals working with the person with diabetes to create a “patient-centered” approach to diabetes care. Following the publication of the DAWN study, there was a call to action to implement evidence-based strategies to improve psychosocial care and self-management education for people with diabetes with support from health-care professionals.^[4,5]

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Just over a decade later, the second DAWN study began as a global initiative between several established National and International Organizations, including the International Diabetes Federation, the International Alliance of Patient Organizations, the Steno Diabetes Center and Novo Nordisk.^[6] The specific aims of the DAWN-2 study were to:

- Improve our understanding of the unmet needs of people with diabetes and those who care for them
- Facilitate dialog and collaboration among all key stakeholders to strengthen active patient involvement and self-management and,
- Establish a cross-culturally validated multinational survey system for assessing and benchmarking the psychosocial and educational aspects of diabetes care delivery.

The study explored how people with diabetes and health-care professionals perceive diabetes care and investigated the needs of individuals in the context of current chronic care, self-management education and psychosocial support. A particularly novel aspect of the DAWN-2 study was the inclusion of a third survey of family members of people with diabetes to assess the effect of diabetes within the family.^[7] As further analysis is undertaken, the three components of the study will permit an assessment of the potential barriers to and facilitators of active and successful management of diabetes among people with diabetes, with support from their family and health-care professionals.

The study was undertaken in 2012 and the first results were presented at the 73rd scientific sessions of the American Diabetes Association in Chicago with simultaneous publication of three papers in *Diabetic Medicine*.^[7-9] Further analyses are on-going and so this review will describe the study and provide the main initial results, with an emphasis on results from India.

MATERIALS AND METHODS

The study comprised three surveys (people with diabetes, family members and health-care professionals) that were completed in 17 countries with a spread across continents and high- to low-income countries.^[6] Participating countries were: Algeria, Canada, People's Republic of China, Denmark, France, Germany, India, Italy, Japan, Mexico, The Netherlands, Poland, Russian Federation, Spain, Turkey, the United Kingdom and the United States of America. In each country, the study was conducted in accordance with the relevant ethics requirements.

Overall more than 15,000 participants took part in the study including 8596 people with diabetes and 2057 family members as well as 4785 health-care professionals (2066 general practitioners, 1350 diabetes specialists,

827 nurses and 542 dieticians). In each country, approximately 500 adults (aged ≥ 18 years) with diabetes took part: 80 had Type 1 diabetes while the remainder had Type 2 diabetes. Those with Type 2 diabetes included 100 people treated with diet and exercise alone, 170 treated with non-insulin medication and 150 were treated with insulin.

In India, people with diabetes and family members were surveyed in Delhi, Mumbai, Kanpur, Chennai, Hyderabad, Bangalore and Kolkata. Health-care professionals were surveyed countrywide.

People were recruited by a number of methods in order to try to make the participants as representative of their country as possible. People with diabetes and family members were approached using the internet or telephone or in-person depending on the methods most relevant to each country while health-care professionals were identified from online panels and databases in each country, as well as telephone lists and physician directories. Potential participants were invited to take part through E-mail or phone. A web-link to a secure server was then provided for participants to complete the survey online. In India, all participating people with diabetes and family members completed the survey in a face-to-face interview lasting 40 min. Health-care professionals either completed an online form or a self-administered questionnaire, taking an average time of 34 min.

The surveys comprised standardized questions adapted from the original DAWN study and modified versions of validated measures, as well as questions developed specifically for this study and addressed a wide range of topics relating to psychosocial issues, education and health-care. Open-ended questions were included to allow participants to share their experiences and have proved a valuable resource to illustrate the responses. The questionnaires were reviewed, approved and tested in English then translated into local languages before being back translated to ensure harmonization.^[6] Full details of the surveys are available elsewhere.

RESULTS

People with diabetes survey

Overall 13.8% of participants reported a World Health Organization (WHO)-5 score ≤ 28 , indicative of likely depression, ranging from 6.6% in Denmark to 23.7% in Algeria.^[8] High diabetes distress the Problem Areas in Diabetes-short form questionnaire (PAID-5) ≥ 40 was reported by 29.6% of participants, ranging from 13% in Denmark and the Netherlands to $> 40\%$ in Italy, Algeria and Turkey. The number of Indian participants with likely

depression was below average while the number with high diabetes distress was higher than average. Indian people with diabetes scored third highest on the WHO-5 psychological well-being scale, after Mexico and Denmark.

Quality-of-life was rated “poor” or “very poor” by 13.9% of participants, with wide between country variation (from 7.6% in Denmark to 29.3% in Japan). Diabetes had a negative impact on all domains investigated, including physical health (62.2%), emotional well-being (46.2%), finances (44.0%), leisure and work activities (38.2% and 35.4% respectively) and relationships with family or friends (20.5%). Nearly 55.5% reported being worried about the risk of hypoglycemia while 39% felt that their medication interfered with their lives.

Psychosocial outcomes were worse for those people with diabetes in worse physical health and with greater experienced diabetes burden. By contrast, better support was associated with better outcomes for well-being and quality-of-life, suggesting that reductions in disease burden and increases in support may lead to better psychosocial outcomes in people with diabetes.

Respondents were most likely to follow self-care advice for medication and diet, but least likely to follow advice on glucose monitoring and foot examination. Again there were significant between country differences in these activities; Indian participants were less likely to follow suggested diabetes medication regimens, undertake blood glucose self-monitoring and foot examination than most other countries. In relative terms, Indian people with diabetes were more likely than other countries with the exception of China to follow a healthy eating plan.

Family member survey

The DAWN-2 study rated the quality-of-life, psychological well-being, likelihood of depression and diabetes distress in family members living with people with diabetes and found 6.9-13.6% of family members reported a “poor” or “very poor” quality-of-life while 8.0-16.2% reported a WHO-5 score ≤ 28 , indicative of likely depression. Indian family members had the lowest prevalence of likely depression and scored third best in terms of psychological well-being.¹⁷

While over half of all family members indicated that their quality-of-life was “good” or “very good,” 45.6% of respondents experienced high distress when thinking about the person with diabetes. Interestingly, Indian participants had one of the lowest scores for this measure, along with Mexico and Russia.

Like people with diabetes, family members also reported

that diabetes had a negative impact on a range of aspects of their lives, including physical health (26.7%), emotional well-being (44.6%), finances (35.2%), leisure and work activities (31.0% and 22.9% respectively) and relationships with family or friends (19.8%).

Diabetes distress was reported by nearly 40% of family members with particularly high rates in India, Algeria and Turkey (all > 60%). 61.3% worried about the risk of hypoglycemic events and a notable burden of diabetes on the family was perceived by over one-third of respondents. Indian family members reported the second highest rate of worrying about hypoglycemia (79.0%), just behind Algerian family members.

39% of family members said they would like to be more involved in the diabetes care, but 37% reported not knowing how to best help the person with diabetes they live with. India, however, had the largest proportion of family members (59.5%) willing to be more involved in diabetes care and the second highest percentage (57.5%) willing to be involved in helping people with diabetes deal their feelings about diabetes.

Health-care professional survey

Provision of diabetes services differed between countries, with many health-care professionals¹⁹ indicating that major improvements were needed across a range of areas including health-care organization (31%, [7-65%]), resources for diabetes prevention (78.5% [60.4-90.5%]), earlier diagnosis and treatment (71.1% [45-86%]), communication between team members and people with diabetes (52.1% [23-85%]), specialist nurse availability (61.4% [27.9-90.7%]) and psychological support (65.7% [40.6-79.6%]). Indian health-care professionals strongly felt that diabetes should be given higher priority (78.6%): this proportion was higher than that for any other country.

Many health-care professionals felt that people with diabetes needed to improve various self-management activities, including eating healthy (93.2%), being physically active (94.6%), dealing with emotions associated with diabetes (63.2%), testing blood glucose (55.4%) and taking medications as recommended (58.4%); the biggest between country difference was for glucose monitoring, which ranged from 29% to 92%.

Health-care professionals recognized the value of actively engaged people with diabetes and suggested that indicating how health-care professionals can best support them (85%), preparing questions before consultations (84%), participating in community activities to improve self-care (84%), finding information on self-management themselves (71%)

would all be helpful in improving diabetes care. Similarly, health-care professionals recognized that involvement of family members of people with diabetes is a vital part of good diabetes care. There were psychosocial benefits for family members in situations where there was lower conflict in relation to diabetes management, an understanding of what help could be offered to people with diabetes and effective collaboration on diabetes management.

Gaps in care

Significant gaps in care were identified for psychosocial and behavioral assessments. For example, while 72% of people with diabetes reported that they had had an assessment of their blood glucose in the preceding year, only 48.5% had been asked about diet and 32% had been asked if they were anxious or depressed.^[8]

There was also a mismatch in the perception of care between people with diabetes and health-care professionals.^[8,9] While over a half of health-care professionals reported asking how diabetes affects their patient's lives, fewer than a quarter of people with diabetes reported having been asked this question. While 73.3% of Indian health-care professionals (highest amongst all 17 DAWN-2 countries) reported having asked this question most of the time or always, only 45.0% of people with diabetes (again the highest among all DAWN-2 countries) said they had been asked this question.

Despite this, health-care professionals recognized the need for resources to provide more person-centered diabetes care with over half requesting improvement in training for effective communication (63%), availability of psychological support and care (63%), availability of diabetes self-management education (61%) and communication among the health-care team (56%).

Education

Despite the recognition of the benefits of self-management education, less than half of people with diabetes participated in any educational program with rates particularly low among Indian participants.^[8] Education of family members was even worse with only a quarter of family members having attended an educational program.^[7] This situation was recognized by health-care professionals of whom 60% reported a need for a major improvement in self-management education (range 26-81%) while a similar number thought that wider access to education would reduce the burden of diabetes.^[9]

Health-care professional training was also an area of concern.^[9] In some countries, up to a third of health-care professionals had received no formal training in diabetes

(median 19.6%). Training was particularly deficient in the psychological aspects of training as only 20% of respondents had training in this area while 58% would like to receive more training in this issue.

Discrimination

19.2% of people with diabetes reported experiencing discrimination, intolerance and lack of support from their community.^[8] This perception was supported by family members of whom 21.5% believed that people with diabetes experienced discrimination because of their diabetes.^[7] Similarly, 32.8% of health-care professionals believed that discrimination was an issue.^[9] Discrimination in India was above average (27.2% vs. 17.6%) with the rates only higher in Turkey. This should be an area of concern as experiencing discrimination because of diabetes was associated with diabetes-related distress for people with diabetes.

Person centered care

The concept of person-centered care was explored in DAWN-2 within the surveys of both people with diabetes and health-care professionals, using validated instruments. Indian health-care professionals scored highest for provision of person centered care, as ranked by people with diabetes (55.9% compared with a mean of 36.1%). In self-reported indices of provision of person-centered chronic illness care, Indian health-care professionals were consistently among the three best nations, along with Mexico and Turkey.

DISCUSSION

The DAWN-2 study is the first multinational study surveying adults with diabetes, adult family members and health-care providers. It has revealed that diabetes remains a significant physical and psychological burden for many individuals with diabetes in all 17 countries surveyed. Self-care activities remain suboptimal in most countries and are in need of improvement. There have been few previous studies of family members of people with diabetes in the literature and DAWN-2 has revealed new insights into the burden of diabetes for family members in terms of distress and reduced quality-of-life. The health-care professional survey has highlighted the concerns of professionals regarding diabetes health-care provision, self-management and training. Although the results show substantial variation in the perceptions of health-care professionals in different countries, health-care professionals across all countries considered the current health-care provision for people with diabetes to be inadequate. Despite technological advances and the availability of improved treatments, current national health-care systems remain poorly equipped to manage and treat people with diabetes effectively.

The adverse psychosocial sequelae of diabetes have been recognized previously in international guidelines that describe the standards of psychological care that people with diabetes should expect. The lessons from the original DAWN study contributed to position statements from the American Association of Diabetes Educators on psychological issues of diabetes management, the chronic care model, to the expanded role of pharmacists in Type 2 diabetes management and the US national standards for diabetes self-management education.^[10-12] Nevertheless despite the progress made over the last decade, the DAWN-2 study clearly indicates that there is still a long way to go.

CONCLUSIONS

DAWN-2 is a multinational, multidisciplinary systematic study that compares unmet needs of people with diabetes and those who care for them in 17 countries across four continents. Its findings should facilitate innovative efforts by those involved in diabetes care to improve self-management and psychosocial support in diabetes, with the aim of reducing the burden of disease in people with diabetes. The challenge will be to translate the findings of DAWN-2 into meaningful changes in practice to improve the lives of those with diabetes.

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