

The Diabetes Attitudes, Wishes and Needs Second Study

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Studies

Study A. Holt RIG, Nicolucci A, Burns KK, et al., on behalf of the DAWN2 Study Group. Diabetes Attitudes, Wishes and Needs second study (DAWN2): cross-national comparisons on barriers and resources for optimal care—healthcare professional perspective. *Diabet Med* 2013;30:789–798.

Study B. Nicolucci A, Burns KK, Holt RIG, et al., on behalf of the DAWN2 Study Group. Diabetes Attitudes, Wishes and Needs second study (DAWN2): cross-national benchmarking of diabetes-related psychosocial outcomes for people with diabetes. *Diabet Med* 2013;30:767–777.

Study C. Burns KK, Nicolucci A, Holt RIG, et al., on behalf of the DAWN2 Study Group. Diabetes Attitudes, Wishes and Needs second study (DAWN2): cross-national benchmarking indicators for family members living with people with diabetes. *Diabet Med* 2013;30:778–788.

Study D. Peyrot M, Egede LE, Campos C, et al. Ethnic differences in psychological outcomes among people with diabetes: USA results from the second Diabetes Attitudes, Wishes and Needs (DAWN2) study. *Curr Med Res Opin* 2014, 1–14. Epub ahead of print (DOI: 10.11485/03007995.2014.947023).

Summary

Objectives. The overall purpose of the Diabetes Attitudes, Wishes and Needs second study (DAWN2) was

to build on the findings of the original DAWN study (1), determine progress made in achieving the needed actions identified by DAWN stakeholders, and explore new methods and strategies for improving diabetes care (2). The primary objective of DAWN2 was to assess current diabetes care and self-management among people with diabetes (PWDs), family members (FMs), and health care professionals (HCPs) and to elucidate determinants of effective treatment and self-management of diabetes (2).

Secondary objectives included establishing national benchmarks for health status, quality of life, self-care, and access to diabetes self-management education and support (DSME/S); assessing access to, and use and benefit of, support from health care teams, family and friends, communities, and society; identifying and understanding the most important facilitators and barriers to person-centered care; and identifying successes, wishes, needs, preferences, and priorities among key stakeholders in diabetes (2).

Design and methods. In Studies A, B, and C, the DAWN2 survey was administered to >16,000 individuals (8,596 adult PWDs [1,368 with type 1 and 7,228 with type 2 diabetes], 2,057 adult FMs of adult PWDs, and 4,785 HCPs [2,066 primary care physicians/general practitioners, 1,350 diabetes specialists, 827 nurses, and 542 dietitians]) in 17 countries across four continents (2–5). The surveys were group-specific, with items

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designed to provide cross-group comparisons on common topics. The questionnaires included those from the original DAWN study (1), as well as validated instruments to assess self-management, attitudes/beliefs, disease impact/burden, distress, health-related quality of life, health care provision/receipt, social support, and priorities for future improvement (2). The majority of the questionnaires were completed online or by telephone, and in-person interviews were conducted in countries with limited Internet access. The recruitment was designed to enroll a representative sample of the diabetes population (in terms of geography, age, sex, education level, and disease status) in each of the participating countries (1).

In Study D (6), the U.S. sample was augmented by independent samples of 1,055 adult PWDs from four ethnic groups: non-Hispanic whites ($n = 447$), African Americans ($n = 241$), Hispanic Americans ($n = 194$), and Chinese Americans ($n = 172$). The objectives of this study were to more specifically assess differences in psychosocial outcomes, risks, and protective factors and to identify correlates of those outcomes (6).

Results. *Study A (HCPs):* Although there were substantial differences, HCPs in all countries considered current health care in diabetes to be inadequate, with up to one-third of professionals indicating that they had not been given any formal diabetes training. Furthermore, all countries indicated that health care systems are poorly equipped to manage diabetes, including health care organization (30.6%, range 7.4–67.1%), resources for diabetes prevention (78.8%, range 60.4–90.5%) and earlier diagnosis and treatment (67.9%, range 45.0–85.5%), communication between HCPs and PWDs (56.1%, range 22.3–85.4%), and specialist nurse (63.8%, range 27.9–90.7%) and psychosocial support availability (62.7%,

range 40.6–79.6%) (3). Sixty percent (range 26.4–81.4%, 12% variance between countries) of HCPs surveyed also indicated that the provision of DSME/S was lacking. Although psychosocial support was considered crucial for diabetes care, only about half (52%) of the HCPs indicated that they ask PWDs how diabetes is affecting their lives. Societal discrimination against PWDs was reported by 32.8% (range 11.4–79.6%) of HCPs (3).

Study B (PWDs): Although there were significant between-country differences for all indicators, no country's outcomes were consistently better or worse than others (4). The number of PWDs with likely depression (World Health Organization-5 Well-Being Index score ≤ 28) was 13.8% (range 6.5–24.1%). Diabetes-related distress (score ≥ 40 on the Problem Areas in Diabetes Scale 5) was reported by 44.6% of those surveyed (range 17.2–67.6%). Overall, quality of life was rated "poor" or "very poor" by 12.2% of participants (range 7.6–26.1%). In addition, PWDs indicated that diabetes had a negative impact on all aspects assessed, ranging from 20.5% on relationship with family/friends to 62.2% on physical health. About 40% (range 18.6–64.9%) reported that their medications negatively affected their ability to live a normal life.

Self-management behaviors were less than optimal in most countries (4). Taking medications and following a diet were reported as most commonly done, with self-monitoring of blood glucose (SMBG) and foot inspections reported as least commonly done, with marked country variation. Only 48.8% reported participation in DSME/S, although 81.1% of PWDs who attended found it very or somewhat helpful. The availability of patient-centered diabetes care and psychosocial support for active engagement was rated as low, with only ~24% reporting that their HCPs had asked how diabetes affected their lives.

Discrimination due to diabetes was reported by 19.2% (range 9.6–30.3%) (4). Results from the open-ended questions indicated that PWDs experienced negative emotional reactions such as anxiety/fear, worry about hypoglycemia and complications, depression, hopelessness, and discrimination. However, PWDs also demonstrated adaptive ways of coping through a positive outlook and sense of resilience in the midst of having diabetes and reported receiving psychosocial support through caring FMs, friends, HCPs, and other PWDs (7).

Study C (FMs): Information about adult FMs of adult PWDs is limited, and this component of DAWN2 provides insight into issues they face (5). Supporting a family member with diabetes was perceived as a burden by 35.3% (range 10.6–61.7%). Although 51.4% of FMs surveyed (range 22.5–76.0%) rated their quality of life as "good" or "very good," distress about the PWD was high, with 61.3% (range 31.5–86.4%) concerned about hypoglycemia. More than half (51.8%, range 46.9–58.6%) indicated that diabetes negatively affected several aspects of their lives, with the greatest effect on emotional well-being (44.6%, range 31.8–63.0%). Many of the FMs responded that they did not know how to best help their loved one with diabetes (37.1%, range 17.5–53.0%) but wanted greater involvement (39.4%, range 15.5–61.7%). Less than one-fourth had participated in DSME/S (23.1%, range 9.4–43.3%), although 72.1% (range 42.1–90.3%) of those who did find it helpful (5).

Study D (U.S. results): To better understand the experiences of people with diabetes in the United States, an independent multivariate analysis was conducted to examine ethnic differences in psychosocial outcomes and risk/protective factors (disease, demographic and socioeconomic factors, health status and health care access/utilization, perceived burden of diabetes, and social support/bur-

den) for these outcomes (6). Separate analyses were done for each ethnicity to determine whether these factors varied across groups. After adjusting for diabetes type/treatment, disease duration, sex, age, and socioeconomic status, there were significant overall group differences for BMI, self-rated health, health index, frequency of hypoglycemia and severe hypoglycemia, frequency of physician and other HCP visits, barriers to access, patient-centered care, worry about hypoglycemia, dietary restrictions, and all measures of social burden and support.

The ethnic minority groups were generally similar in their results and all varied significantly from the white non-Hispanic PWDs. They reported more positive psychological well-being and better quality of life, experienced less negative impact, and felt more empowered about diabetes compared to the white non-Hispanic PWDs. The only exception was diabetes-related distress, with all ethnic minority groups reporting significantly greater levels of distress than non-Hispanic whites. Among the U.S. participants, 64% of PWDs and 35% of FMs took part in formal DSME/S. Most (78 and 70%, respectively) found it helpful (6).

Conclusions. Table 1 shows key findings from each of the populations studied in DAWN2 and the differences among the four ethnic groups studied in the United States. Both the overall results and results from each component demonstrate that diabetes represents a significant burden for PWDs, FMs, HCPs, health care systems, and society.

Commentary

The original DAWN study, completed in 2001 (8), indicated that diabetes self-management was less than optimal, in large part because of psychosocial issues. Diabetes-related distress and depression were common but rarely assessed or treated. In addition, access to team care and communication

DAWN2 Studies	Key Findings
Study A: HCPs' perspective	<ul style="list-style-type: none"> The original DAWN study found that diabetes is often associated with multiple psychosocial problems that are barriers to self-management behaviors and that current health care resources are sometimes poorly equipped or used to provide needed support. In DAWN2, HCPs continue to recognize the importance of improving health care organization, as well as addressing emotional issues and improving self-management for people with diabetes. In addition, access to quality care is perceived to be poor and more training in many aspects of diabetes is needed.
Study B: PWDs' perspective	<ul style="list-style-type: none"> Diabetes affects the physical, emotional, social, and financial aspects of PWDs' lives and presents significant psychosocial challenges. The majority of PWDs are not engaged by HCPs, but this a high priority for most. There are gaps in the availability of psychosocial support, self-management education, and person-centered diabetes care. Diabetes-specific discrimination is prevalent.
Study C: FMs' perspective	<ul style="list-style-type: none"> Diabetes affects the lives of FMs, causing significant burden and distress. Psychosocial problems of FMs are barriers to their involvement, but they are also an underused resource for support. Health care systems are limited in the provision of psychosocial support and education to families.
Study D: U.S. perspective	<ul style="list-style-type: none"> Psychosocial outcomes, risks, and protective factors differ across and between the ethnic groups studied. The majority of PWDs want to improve self-management behaviors (diet and exercise). There is a substantial amount of diabetes-related distress among PWDs and their FMs, and those in ethnic minority groups experience more distress than non-Hispanic whites. Having a large social support network is related to better outcomes.

between PWDs and HCPs was associated with better outcomes.

Although there has been an emphasis on personalized approaches to diabetes, shared decision-making,

patient engagement, culturally relevant care, and the development of Patient-Centered Medical Homes in recent years, DAWN2 indicates that diabetes care and self-management

TABLE 2. Provider-Based Strategies

At the time of diagnosis:

- Create a person-centered care environment.
- Ask PWDs and their FMs about their greatest fears and feelings about diabetes.
- Inform PWDs and their FMs that it is common to experience distress and other negative emotions to normalize their experience.
- Stress the importance of their role in self-management and the importance of DSME/S.
- Offer referral for DSME/S and psychosocial issues to PWDs and their FMs.
- Stress the importance of taking diabetes seriously.
- Direct PWDs and their FMs to appropriate community organizations and resources.

During follow-up clinical visits:

- Create a person-centered environment.
- Develop a collaborative partnership with PWDs and their FMs.
- Begin each visit by asking PWDs to identify their struggles, concerns, feelings, questions, and progress toward self-determined metabolic, psychosocial, and behavioral goals.
- Ask PWDs and FMs how diabetes is affecting their daily lives.
- Actively listen and explore ongoing issues and needs.
- Include FMs in the encounters and provide needed education and support.
- Reinforce education provided in a DSME/S program.
- Ask for the PWDs' opinions about SMBG results and other laboratory and outcome measures.
- Review and revise diabetes care plans as needed based on assessment of their effectiveness by PWDs as well as the provider, incorporating metabolic and psychosocial outcomes and impact on daily life.
- Provide ongoing information about the costs and benefits of therapeutic and behavioral options to promote engagement and shared decision-making.
- Take advantage of teachable moments that occur during each visit.
- Ask PWDs to "teach back" what you have discussed at the end of each visit.
- Ask PWDs to identify one thing they will do differently to manage their diabetes before the next visit.
- Provide information and resources for behavior change, problem-solving strategies, and psychological support to assist PWDs in overcoming barriers to self-management.
- Assess and address diabetes-related distress and depression.
- Normalize ongoing negative feelings and refer PWDs for treatment of depression as needed.
- Abandon traditional dysfunctional models of care (e.g., adherence, compliance, and provider-driven care) and work collaboratively in partnership with PWDs and their FMs.

continue to be lacking, that PWDs and their FMs still experience psychosocial problems as a result of diabetes, and that changes in the health care system have not yet been adequate

to improve the experience of PWDs and HCPs. The discrepancy between HCPs and PWDs in assessing the impact of diabetes on daily life (51 vs. 24%) and the numbers of PWDs and

FMs who have not received formal DSME/S are of particular concern.

The DAWN2 supplemental U.S. component demonstrated that the ethnic minority groups studied remain underserved and experience greater diabetes-related distress and burden (6). Although other psychosocial measures were more positive for these groups, because diabetes-related distress negatively affects A1C and self-management behaviors, it is likely the most important of these outcomes (9). However, PWDs in minority groups reported more family and social support. Involving FMs in clinical care and DSME/S, teaching FMs how to be more effective supporters, and continuing to emphasize culturally relevant care are all strategies that have the potential to improve outcomes.

DAWN2 reinforces the message that HCPs need to better understand the priorities, psychosocial needs, and goals of PWDs and FMs and the personal context of their daily decision-making and self-management efforts (10). Table 2 outlines strategies that can be used to address these essential issues in clinical care (11). Although health care system changes are clearly needed, DAWN2 provides a call to action for individual HCPs to adopt a person-centered care approach that responds to the identified needs of both PWDs and their FMs.

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Duality of Interest

Martha M. Funnell received payment from Novo Nordisk as a consultant at the DAWN2 summit. Stuart Bootle received payment from Novo Nordisk as a consultant at the DAWN2 Summit and for workshop

facilitation and lecturing in the United Kingdom. Heather L. Stuckey served as the lead qualitative researcher for DAWN2 and received payment as a consultant from Novo Nordisk. No other potential conflicts of interest relevant to this article were reported.

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