

The Diabetes Attitudes, Wishes, and Needs (DAWN) Program: A New Approach to Improving Outcomes of Diabetes Care

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The Diabetes Attitudes, Wishes, and Needs (DAWN) program is an international partnership effort to improve outcomes of diabetes care by increasing the focus on the person behind the disease, especially the psychosocial and behavioral barriers to effective diabetes management. DAWN was initiated by an international survey of > 5,000 people with diabetes and almost 4,000 diabetes care providers. The DAWN program has facilitated a number of concrete initiatives to address the gaps in diabetes care identified by the DAWN study.

Why Do We Need DAWN?

Diabetes is one of the major world health problems. Recent estimates from the World Health Organization predict that if current trends continue, the number of people with diabetes will more than double, from 176 to 370 million people by 2030.¹ Diabetes is already the single most costly health care problem in Westernized countries. Among those diagnosed with the disease, at least half still do not achieve satisfactory glycemic control, despite the availability of effective treatments.² As a consequence, millions of people with diabetes are at elevated risk of suffering needlessly from serious complications of the disease. With the growing number of people with diabetes, there is an urgent need to find better ways of curbing the human and economic burden of this chronic progressive disease, through prevention, detection, and treatment. A review of the literature suggests several important areas that have the potential to address these problems.

Suboptimal diabetes self-management has been identified by several

studies as one of the possible causes of poor outcomes of diabetes care in general practice.^{3,4} A multitude of research studies, mainly in the Western world and with relatively small patient samples, has indicated the potential importance of a multitude of psychological, social, and behavioral factors for patient self-management.^{5,6} Access to patient-centered self-management support and education has been shown in several studies to improve outcomes of diabetes care.⁷

Psychosocial research points to an integral role of psychosocial issues in all aspects of diabetes care,⁸ and in particular comorbid depression is associated with impaired self-management and metabolic control. Psychological treatment may help to improve both quality of life and diabetes self-management.⁹ Furthermore, monitoring of psychological health may improve patient-reported outcomes as part of ongoing diabetes care.¹⁰

In terms of the structure and processes of care, effective communication between patients and providers has been suggested to be important for optimal treatment outcomes.^{11,12} For instance, application of motivational interviewing techniques has been shown to improve the success rate of behavior change consultations.¹³

Access to a coordinated interdisciplinary diabetes care team to offer appropriate care, whether the need is self-management education, medical advice, or psychosocial support, has been identified as an important factor for improving treatment outcomes in diabetes.^{14,15}

Delayed initiation of medication therapies to prevent long-term com-

lications is commonly observed in general practice settings. Both patient and provider beliefs appear to contribute to the delayed use of effective therapy (e.g., misconceptions of the consequences of initiating medication, that medication is not efficacious or may have serious side effects).^{16,17} These factors lead to a reluctance to intensify treatment regimens, which may be overcome through improved communication.

What Is DAWN?

DAWN is an international collaborative program initiated in 2001 by Novo Nordisk in partnership with the International Diabetes Federation and an international expert advisory panel representing leading spokespeople for medical, educational, psychological, and advocacy issues related to improving a person-centered approach to diabetes care. Panel members were from Denmark, France, Germany, India, Japan, the Netherlands, the United Kingdom, and the United States. National activities are developed by multidisciplinary national expert groups drawing on relevant best practices for putting DAWN into action.

The goal of DAWN is to improve outcomes of diabetes care by increasing the focus on the person behind the disease, especially the psychosocial and behavioral barriers to effective diabetes management. DAWN was initiated by an international study designed to identify a broad set of attitudes, wishes, and needs among diabetes patients and care providers (physicians and nurses) in order to lay a foundation for national and international efforts to improve diabetes care.¹⁸ The DAWN study examined several factors related to quality of

diabetes care: levels of diabetes self-management and psychological distress among people with diabetes, quality of relationships between people with diabetes and their care providers, collaboration among diabetes care providers (team care), and barriers to effective medication therapy for diabetes.

Once the DAWN study was completed, the results provided the impetus for a number of initiatives designed to remedy the problems identified. Some of these initiatives were already underway, and the results stimulated support for their development; other initiatives grew out of the collaborative efforts of the international community exposed to the findings of the DAWN study.

The DAWN Study

All data are self-reports gathered during 2001 by structured interviews conducted face-to-face or by telephone, using DAWN questionnaires that had been developed based on a literature review and focus groups in eight countries and translated into the languages of the countries studied. Interviews were conducted in 11 regions (representing 13 countries): Australia, France, Germany, India, Japan, the Netherlands, Poland, Scandinavia (Sweden, Denmark, and Norway), Spain, the United Kingdom, and the United States. The Scandinavian samples were evenly divided among the three countries.

The study was conducted with three independent samples. The first sample consisted of 2,705 physicians with a quota of 250 per region: 200 in primary care and 50 specialists (endocrinologists and diabetologists with 2 years of experience and treating > 50 diabetes patients per month). The second sample consisted of 1,122 nurses with a quota of 100 per region: 50 specialists (treating > 50 people with diabetes per month) and 50 generalists. Caring for at least five people with diabetes per month was an inclusion criterion for the study, and only one provider was selected from a given practice.

Physician respondents were predominantly male (72.6%), whereas nurses were predominantly female (95.2%). Both physicians (69.5%) and nurses (69.0%) worked in urban

sites, as opposed to rural and suburban sites. Physicians had a longer average duration of practice (15.9 years) than nurses (10.6 years).

The third sample consisted of adults with type 1 or type 2 diabetes with a quota for each region of 250 people with self-reported type 1 diabetes and 250 with self-reported type 2 diabetes. For the purpose of analysis, people were classified as having type 1 diabetes if they were diagnosed with diabetes before age 40 and treated with insulin both at diagnosis and at the time of the survey; others were classified as having type 2 diabetes. Respondents who did not provide information necessary to classify type of diabetes according to this algorithm were deleted from the analyses, leaving a usable sample of 5,104.

People with diabetes were divided almost equally by sex (54.0% female) and lived primarily in urban areas (58.0%). The median age at which formal education was completed was 17 years. Approximately one-third were classified as having type 1 diabetes; Japan was an anomaly with < 5% having type 1 diabetes. Compared to people with type 2 diabetes, those with type 1 diabetes had a younger average age (38.0 vs. 59.3 years) and a longer average duration of diabetes (19.2 vs. 11.2 years).

What DAWN Taught Us

The results reported here draw on a number of forthcoming articles and analyses presented at research conferences.¹⁹⁻²⁵

Adherence

Reported adherence with recommendations for diet, exercise, medication

taking, glucose testing, and appointment keeping was low. Fewer than one in five people with diabetes (19.4% of those with type 1 diabetes and 16.2% of those with type 2 diabetes) reported that they completely complied with all aspects of their prescribed regimens. Providers rated adherence substantially worse than did people with diabetes (7.3% of providers estimated that their typical type 1 patient completely complied with all aspects of their prescribed regimens, and 2.9% of providers estimated the same for their typical type 2 patient).

Distress

People with diabetes reported that diabetes-related distress is high at diagnosis (85.2% reported feeling shocked, guilty, angry, anxious, depressed, or helpless). Long after diagnosis (mean duration of almost 15 years), problems of living with diabetes were prevalent, including fear of future complications and resulting social disabilities, as well as immediate social and psychological burdens (Table 1). Three of four (73.6%) reported at least one of these fears or burdens. Providers reported that the majority of their patients with type 1 or type 2 diabetes experience psychological problems (67.9 and 65.6%, respectively). Almost half of all people with diabetes in the DAWN study had poor well-being according to the WHO-5 well-being index.¹⁹

There was a linkage between poor adherence and psychological problems. The majority of providers (68.3%) reported that psychological problems influence regimen adherence. Moreover, a poor reaction at

Table 1. Percentage of Patients Experiencing Various Aspects of Diabetes-Related Distress

Diabetes-related distress	Percentage of respondents who agree
I feel stressed because of my diabetes.	32.7
I feel burned out because of my diabetes.	18.1
I feel that diabetes is preventing me from doing what I want to do.	35.9
I am constantly afraid of my diabetes getting worse.	43.8
I worry about not being able to carry out my family responsibilities in the future.	30.1
My diabetes causes me worries about my financial future.	25.8
My family and friends put too much pressure on me about my diabetes.	14.7
The community I live in is intolerant of diabetes.	13.6

diagnosis (characterized by an inability to accept the diagnosis and a strong negative emotional response) was associated with a variety of poor patient-reported outcomes, including regimen nonadherence (Figure 1).

Despite the widespread prevalence of diabetes-related distress and its important negative consequences, only a small minority of people with diabetes (3.3%) had received psychological treatment for diabetes-related problems within the 5 years prior to the survey.

Patient-Provider Relationships

The quality of patient-provider relationships was rated high by patients; 88.8% reported that they have a good relationship with the people who care for their diabetes. However, most providers reported that they need to better understand the psychological consequences of diabetes (69.8%) and the various ethnic cultures that they deal with (78.8%).

Provider Collaboration

Team care was less than optimal (Table 2). To assess levels of team care, physicians were asked how many of seven providers a typical patient of theirs saw on an annual basis (primary care practitioner, diabetes specialist physician, diabetes nurse, dietitian/nutritionist, eye doctor, foot doctor, behavioral specialist). Most providers (65.6%) said their diabetes patients saw two or fewer providers in addition to themselves; specialist physicians were more likely than primary care physicians to report

Table 2. Percentage of Physicians Reporting That Their Typical Patient Sees Various Diabetes Care Providers Annually

Discipline Seen	Respondent	
	Primary Care Physician	Diabetes Specialist Physician
Primary Care Physician	NA	39.2
Diabetes Specialist Physician	38.6	NA
Diabetes Specialist Nurse*	24.6	35.6
Dietitian/Nutritionist*	31.3	40.9
Eye Specialist	67.0	64.4
Foot Specialist	32.5	35.7
Behavioral Specialist*	6.0	14.0

Data are %.
*Significant ($P < 0.05$) difference between primary care and diabetes specialist.

four or more additional providers (22.0 vs. 12.0%). Annual appointments were common only for eye doctors (approximately two or three respondents described such visits as typical), and typical appointments with most other providers were reported by only one in three participants, with behavioral specialists reported as team members for the typical patient by < 10% of physicians. Only half of people with diabetes (51%) felt that their diabetes health care providers talked to each other about their care.

Barriers to Use of Effective Medication Therapy

Many people with diabetes have worries about starting diabetes medication and intensifying existing medication regimens. And providers are not eager to use medication to achieve treatment goals. Of those taking anti-hyperglycemic medication, one in six (16.6%) feels that their treatment is

too complicated, and one in three (33.7%) is tired of complying with their medication regimen. Of those not taking insulin and who feel that their diabetes is not well controlled, only one in four (26.9%) believes that insulin would help them to manage their diabetes better. Nearly one in two providers (43.4%) prefers to delay initiation of oral medication until it is “absolutely essential.” And only half (49.2%) of health care providers believe that earlier use of insulin would decrease the overall cost of diabetes care. Patients who are resistant to effective medication regimens and who are treated by providers who share their resistance are likely to experience delays in the intensification of treatment even in the face of persisting need.

Summary

The DAWN study has identified several important gaps in the management of diabetes across a number of countries. Diabetes self-management is less than optimal and is compromised frequently by diabetes-related distress, which often is not treated. Although the quality of patient-provider relationships is generally good, providers need a better understanding of the social and psychological problems that people with diabetes face. Team care is uncommon, with few providers providing their patients with comprehensive multidisciplinary care. People with diabetes and health care providers often resist initiating effective medication therapies. These problems combine and reinforce one another, leading to an unnecessary increase in the burden of diabetes.

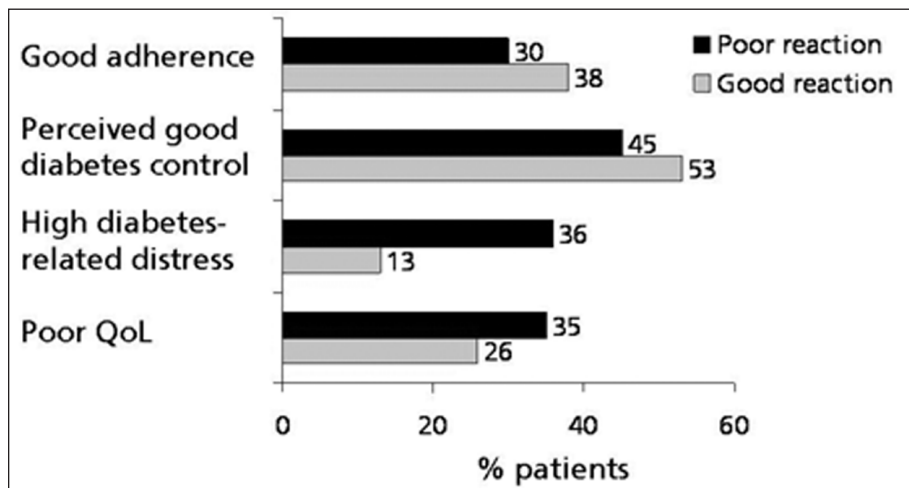


Figure 1. Poor reaction to diagnosis predicts later problems. QoL, quality of life.

While these findings confirm what many diabetes health care professionals already believe, the DAWN study provided the first quantitative data from a large-scale, international study regarding both the magnitude and nature of these problems. Furthermore, the study offered a host of new insights about concordance and the lack thereof in the perceptions of different participants in diabetes care. Importantly, the study identified major gaps in the provision of diabetes care today, including a failure to take fully into account the individual barriers to achieving full health and quality of life among people with diabetes.

Implications of the DAWN Study

To transform the wealth of insights from the DAWN study into concrete actions to improve diabetes care, two international DAWN summits were held, each attended by > 100 leading health care professionals, researchers, decision-makers, people with diabetes, media personnel, and representatives of major nongovernmental diabetes organizations and the pharmaceutical industry. The 1st International DAWN Summit was held in Oxford, United Kingdom, in April 2002.²⁶ This 2-day meeting involved presentation and discussion of the primary DAWN findings. Major themes were identified through discussion of findings in discipline-specific and country-specific break-out groups.

The 2nd International DAWN Summit was held in London in November 2003 with a goal of initiating concrete action.²⁷ The 2-day meeting included presentations from government policymakers, representatives of the International Diabetes Federation and the World Health Organization, and leading researchers. The common theme was defining feasible actions that could be taken to address the gaps in diabetes care identified by the DAWN study. Best practices were shared by speakers from countries that had already taken action based on the DAWN findings at a national level. These presentations laid the foundation for multidisciplinary, multinational workshops in which participants could identify concrete and feasible actions that could be taken to help

overcome the barriers to optimal health and quality of life faced by people with diabetes. In plenum, voting systems enabled all participants to take part in the final selection of key goals for future action. Based on the key findings of the DAWN study, the following five goals were confirmed for concerted advocacy and action to improve diabetes care worldwide (Table 3).^{27,28}

1. Promote active self-management.

Active self-management is a key determinant of treatment outcome in diabetes, and therefore the diabetes care team's ability to facilitate active self-management and patient involvement in the care process is central to achieving optimal treatment outcomes. Health care professionals should encourage better self-management by taking into account individual patient's circumstances, needs, and resources when creating treatment plans and considering psychosocial barriers to self-management as an integral part of the care process.

2. Enhance psychological care.

Although many people with diabetes cope well and live normal, healthy lives with diabetes, far too many suffer emotionally without receiving basic psychosocial support. Improved access to health care professionals and psychologists trained in identifying

patients' needs and providing counseling and psychosocial support to people with diabetes is needed in order to diminish the psychological burden of living with diabetes and overcome the psychological barriers to effective disease self-management.

3. Enhance communications between people with diabetes and health care providers.

Effective patient-centered communication is considered a prerequisite for understanding and addressing the individual psychosocial barriers to diabetes self-management in daily care. Because enhanced communication requires the active involvement of both the person with diabetes and health care professionals, efforts in this area should involve initiatives to empower and engage both people with diabetes as well as health care professionals to communicate effectively. People with diabetes should be supported in taking responsibility for their own disease and expressing their treatment and support needs clearly to their health care professionals.

4. Promote communication and coordination between health care professionals.

Diabetes is a complex condition, and its effective management requires a coordinated multidisciplinary care approach. The role of every team member should be enhanced, and strategies are needed to promote team building and dialogue among all diabetes professionals to ensure a coherent, integrated approach to optimizing treatment.

5. Reduce barriers to effective therapy.

Patient understanding of the consequences of not treating diabetes optimally requires that health care providers give the information and support necessary to enable patients to make informed decisions about intensification of therapy. All health care professionals should be aware of the health implications of postponing necessary therapy and should enable patients to make genuinely informed choices about therapy. This requires increased awareness and information about diabetes treatment options that suit the individual lifestyle and treatment needs of each patient.

Table 3. DAWN Goals and Strategies

<p>Goals of the DAWN Program</p> <ol style="list-style-type: none"> 1. Promote active self-management. 2. Enhance psychological care. 3. Enhance communications between people with diabetes and health care providers. 4. Promote communication and coordination between health care professionals. 5. Reduce barriers to effective therapy. <p>Strategies to Achieve DAWN Goals</p> <ol style="list-style-type: none"> 1. Raise awareness and advocacy. 2. Educate and mobilize people with diabetes and those at risk. 3. Train health care providers and enhance their competencies. 4. Provide practical tools and systems. 5. Drive policy and health care systems change. 6. Develop psychosocial research in diabetes.

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Translating Goals Into Action

The DAWN Call to Action^{27,28} was developed on the basis of international dialogue among patients, educators, physicians, health care researchers, politicians, and nongovernmental organizations. It identifies concrete strategies that can be implemented at the local, regional, national, and international levels to promote the achievement of the five goals of the DAWN program and the translation of DAWN study insights into real quality-of-life improvements on a large scale (Table 3). Guided by this framework, numerous initiatives have been proposed and implemented by groups and organizations in different countries. Below, we define the strategies and provide examples of these initiatives.

Strategy 1. Raise awareness and advocacy.

Those individuals and organizations with an understanding of the benefits of providing psychosocial support for people with diabetes must play an active role in sharing their knowledge with their peers and raising awareness in the public about the importance of changing our approach to diabetes care and focusing more on the attitudes, wishes, and needs of people with diabetes and their caregivers.

Examples of action. The International Diabetes Federation (IDF) published a special issue of its journal *Diabetes Voice*, which was distributed in 140 countries; this issue was dedicated to the implications of the DAWN study and the resulting international DAWN Call to Action and triggered many new DAWN activities.²⁸ In the United States, the American Diabetes Association's patient magazine, *Diabetes Forecast*, highlighted the key insights from the DAWN study, reaching millions of readers nationwide.²⁹ In the Arabic world, Asia, Europe, and Latin America, lay media coverage of DAWN findings has helped reach out to millions more people at risk for and with diabetes.

Strategy 2. Educate and mobilize people with diabetes and those at risk.

People with diabetes and those at risk of developing the condition need

access to empowering information in order to make informed decisions about their health and quality of life. As experts in the management of their own condition, people with diabetes need to be engaged to play a key role in new approaches, tools, and guidelines for patient-centered care. People with diabetes inform health care providers, policymakers, and others about the needs and wants of people with diabetes.

Examples of action. The Assisting Young Diabetics in Egypt Project successfully offered psychological support and therapeutic patient education to > 2,000 children and families with diabetes over just 2 years' time. This project was identified by the DAWN international advisory board as the winner of the 2004 DAWN Award. The DAWN international and national advisory boards involve people with diabetes, and the DAWN summits offer people with diabetes opportunities to speak to international audiences about their needs. In Germany and the Netherlands, concrete activities include the issuance of diabetes passports to all people with diabetes to encourage active self-management and clear communication and agreement among patients and providers about the mutual responsibilities involved in optimal diabetes management. In New Zealand, people with diabetes attending a large diabetes center were offered a patient involvement form before each consultation to encourage active patient participation and clear communication during diabetes visits.

Strategy 3. Train health care providers and enhance their competencies.

In order to overcome the psychosocial barriers to effective diabetes management identified by DAWN, health care systems need to identify ways to improve the identification of these barriers and develop approaches to effectively address these in general practice settings. Training opportunities should be made more easily available for diabetes health care providers, along with simple and practical strategies to promote sustainable institutionalization of feasible person-centered approaches to delivering diabetes care.

Examples of action. In the United States, a continuing medical education program on how to put DAWN into clinical practice was created for diabetes educators based on one of several DAWN symposia held as part of the annual meetings of the American Association of Diabetes Educators.²⁰ In Poland, the DAWN study revealed a major national need for training primary care in an integrated medical and psychosocial approach to treating type 2 diabetes. Using DAWN as a foundation, train-the-trainer workshops and simple daily assessment tools were developed and disseminated widely in that country, and today > 4,500 Polish health care professionals have been trained in both the psychological and medical aspects of treating diabetes. In Germany, > 1,000 general practitioners, and diabetes specialists and nurses were trained in skills focusing on communication and psychosocial matters in order to increase patient empowerment. Drawing on experiences from > 300 diabetes nurse specialists from 14 countries who took part in a new DAWN workshop concept for diabetes teams, a set of diabetes team workshops and DVD- and video-enhanced training tools was developed in 2004; these have been adopted by many providers in countries such as Australia, Germany, Israel, Sweden, the United Kingdom, and the United States.

Strategy 4. Provide practical tools and systems.

The adequate identification of psychosocial and educational needs requires first and foremost effective listening and communication skills on the part of health care professionals, an essential element of the chronic illness care model.³⁰ In addition, patient self-report assessment tools and decision-support tools can facilitate inclusion of psychosocial aspects in routine clinical encounters between health care professionals and patients to improve patients' well-being.^{10,31}

Examples of action. In response to the DAWN study, several countries have introduced internationally endorsed measures of psychological well-being, diabetes-related distress, and barriers to self-management into quality-of-care monitoring systems.

During the period from 2002 to 2004, > 15,000 people with diabetes from > 15 countries have completed the WHO-5 well-being index and other diabetes-specific items from the DAWN survey questionnaire, offering a wealth of new insights about the needs of people with diabetes and the associations between psychological variables, perceived quality of care, and clinical outcomes. A one-page patient form was developed in New Zealand and several other countries for use by patients prior to each consultation to help identify relevant psychosocial issues and promote more active involvement of the patient in the consultation and decision-making process.

Strategy 5. Drive policy and health care systems change.

In diabetes management guidelines, reimbursement systems, and quality systems, the psychosocial needs of people with the condition should be approached with the same priority as their medical needs. Toward this end, governments and health care systems can be lobbied to adopt the chronic care model advocated by the World Health Organization.

Examples of action. The DAWN program has facilitated two international guideline meetings in 2004 and 2005 aimed at promoting consensus regarding evidence-based recommendations for psychosocial care for people with diabetes. At the DAWN guideline meeting in Wuerzburg, Germany, in April 2005, experts in psychosocial aspects of diabetes from 12 different countries developed a joint statement that “diabetes mellitus is an emotionally and behaviorally demanding condition, and psychosocial factors are integral to its prevention, diagnosis, treatment, and outcomes.”

In response to the DAWN Call to Action, the national care guidelines in Japan were updated to include psychosocial treatment recommendations for diabetes, and the Psychology and Behavioral Medicine Council of the American Diabetes Association initiated a working group to develop psychosocial care guidelines. In 2003 and 2004, the Netherlands and Germany have taken steps towards implementing evidence-based psychosocial guidelines in diabetes,³² and the IDF

will be publishing its global treatment guideline by the end of 2005 with a separate section on psychosocial care in diabetes.

Strategy 6. Develop psychosocial research in diabetes.

More collaborative clinical research on psychosocial aspects of diabetes needs to be conducted to demonstrate the health and economic benefits to society of improved patient-centered diabetes care and adoption of the call to action specified here. A better understanding is required of the effective patient-centered approaches to support self-management and enhance long-term health and quality of life of people with diabetes.

Examples of action. The European Depression in Diabetes Research Consortium (EDID), a multinational research initiative stimulated by the DAWN Call to Action, has begun to assess the psychosocial burden of diabetes by promoting the use of a common set of measures so that national comparisons can be made.³³ In countries such as Argentina and Israel, evaluation studies are ongoing to assess the impact of intervention and education programs aimed at bringing the DAWN findings into action. A multicountry DAWN study in Europe is examining the feasibility of daily use of psychosocial assessments in primary care settings in Europe. In the United States, a large DAWN research initiative has been launched to evaluate specific approaches to increasing active participation in diabetes care among people with diabetes from different ethnic groups.

Next Steps

The paradigm for treating diabetes care is changing on a global scale. Governments, health insurers, health care professionals, and nongovernmental organizations are increasingly recognizing the importance of new partnerships and new ways of adopting more effective approaches to helping people with diabetes better self-manage the medical and psychosocial challenges associated with the disease. The DAWN study has contributed to highlighting the urgency of making this change and identifying where efforts need to be focused at the global and national levels. The DAWN

program has stimulated momentum to support national action and provided a platform for sharing best practices worldwide.

A key challenge for putting the insights from the DAWN study into effect is the ongoing promotion of broad dialogue and the creation of sustainable partnerships involving all key parties in diabetes care, with people with diabetes at the center. Only through such partnerships can the proposed new approach to diabetes be fully embedded into whole communities and national diabetes programs. Furthermore, an increased focus on the attitudes, wishes, and needs of special populations (including children and adolescents with diabetes and people with diabetes in underprivileged communities or who belong to ethnic minorities) is critically needed to identify opportunities to improve care and quality of life for these groups.

Continuous and increasing collaborative efforts are needed to transform care for diabetes and other chronic diseases from the acute to the chronic care model. Future focus needs to be placed on implementation and translational research, with international sharing of effective tools for furthering a person-centered approach to chronic disease management and prevention.

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