Behavioral Science Research in the Prevention of Diabetes

Status and opportunities

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Recent studies show diabetes can be prevented. Growing knowledge of its biological bases opens further prevention opportunities. This article focuses on behavioral science research that may advance these opportunities. An ecological model guides attention to how prevention research may be pursued at the individual, group, or community levels. Three key areas are reviewed: risk communication, screening, and preventive interventions. Research on diabetes risk communication is limited but suggests that many are relatively unaware of risks and may have misconceptions about the disease. Amid policy debates and research regarding the potential benefits and costs of screening, identification of diabetes itself may be risky in terms of psychological and social consequences. The Diabetes Prevention Program and other studies make clear that diabetes can be prevented, both by the combination of weight loss and physical activity and by medications. Research needs to address promoting these methods to individuals as well as to groups and even whole communities. Fundamental as well as applied research should address how risks of diabetes are understood and may be communicated; how to enhance benefits and minimize psychological and other risks of screening; how to promote healthy eating and weight loss, physical activity, and appropriate use of medications to prevent diabetes; and how to reduce socioeconomic and cultural disparities in all these areas.


Preventing type 2 diabetes is now possible, as demonstrated by the Diabetes Prevention Program (DPP) (1) and other studies (2,3). Exciting developments in understanding the genetics and pathophysiology of diabetes will expand opportunities to prevent it. Behavioral science will be critical to the realization of these opportunities. As reviewed in this article, prevention of diabetes will benefit from advances in three key areas of behavior science: 1) how we conceptualize, assess, and communicate risk; 2) how we identify those at high risk; and 3) how we reduce risk or prevent it in the first place, including among disadvantaged groups. This article is based on a group report from the November 1999 Conference on Behavioral Science Research in Diabetes sponsored by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

ECOLOGICAL MODEL OF BEHAVIOR — The ecological model in Fig. 1 provides a framework for conceptualizing prevention. It outlines influences on behavior that operate within the individual, within family, and at a community level, including organizational, cultural, governmental, and policy influences. The model points to the importance of changes at multiple levels to encourage healthier communities (4). Taking up this approach, a recent report of the Institute of Medicine on promoting health stated one of two “overarching recommendations” as “interventions on social and behavioral factors should link multiple levels of influence (i.e., individual, interpersonal, institutional, community, and policy levels)” (5).

The ecological model has gained popularity in planning interventions, but it is also helpful in other areas, such as analysis of risk perception. For example, research may study differences in perceptions of risk among health care professionals, individuals with a disease, and the general public.

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Received for publication 29 June 2001 and accepted in revised form 6 December 2001.

Abbreviations: ADA, American Diabetes Association; AHRQ, Agency for Healthcare Research and Quality; DPP, Diabetes Prevention Program; FPG, fasting plasma glucose; IGT, impaired glucose tolerance; NIDDK, National Institute of Diabetes and Digestive and Kidney Diseases; OGTT, oral glucose tolerance test. A table elsewhere in this issue shows conventional and Système International (SI) units and conversion factors for many substances.
RISK OF DIABETES — An estimated 15 million people in the U.S. have diabetes. Over 90% have type 2 diabetes. Pertinent to risk communication, it is estimated that at least one-third of individuals with type 2 diabetes do not know they have it, having not had appropriate screening and having no recognizable symptoms.

In addition to diabetes itself, impaired glucose tolerance (IGT) is a precursor to type 2 diabetes and is associated with increased risk of macrovascular disease. In addition to the 15 million people with diabetes, IGT has a prevalence of ∼11% in the U.S. population. The combined prevalence is 42% among older adults and is also heightened in ethnic minority groups.

The concept of risk does not apply only to the diagnosis. Diabetes is the leading cause of new cases of blindness in adults, the most common cause of end-stage renal disease, and the leading cause of nontraumatic amputations of lower limbs. Diabetes is associated with a severalfold increase in risk of cardiovascular disease. In summary, the risks associated with diabetes are enormous when diabetes is not controlled, prevented, or delayed.

CONCEPTUALIZATION AND COMMUNICATION ABOUT RISK OF DIABETES — In assessing risk and designing risk communications, it is helpful to distinguish among mental models, decision analysis, and risk communication.

Mental models of risk
Perceived risk reflects a variety of factors such as exposure and susceptibility to a risk, severity of consequences, the opportunities for control of the risk, and the certainty surrounding those estimates. Lay people bring to any risk a web of beliefs, called “mental models,” that reflect some mix of knowledge, misinformation, and ignorance. These mental models may be quite different than scientific models of well-understood phenomena. Individuals’ understanding of risk advances by integrating better information with their mental models. Mental models are critical to risk communication because, to be effective, communication needs to be understandable within an audience’s mental model.

A common approach to studying mental models compares a normative analysis (such as an “expert decision model” of what facts about a decision are most worth knowing) with a descriptive analysis of common mental models (what people currently believe) (9,10). The few studies that have compared expert and lay risk perceptions in diabetes indicate appreciable gaps (11,12). For example, relative to scientific estimates, Meltzer and Egleston (13) found that individuals with type 1 diabetes overestimated both their risk of complications and the benefits of intensive treatment.

Model building and specification allow development of communications to reduce gaps between mental and normative models (14). In diabetes, even identifying normative or expert models is challenging. Estimates of risks and benefits of risk reduction need to reflect multiple forms of morbidity as well as appreciable scientific uncertainty. Etiologies of both type 1 and type 2 diabetes are complex. Although consensus exists around the range of factors in the development of diabetes, there is uncertainty regarding their specific roles (6,15). Further complicating the public’s mental models is the existence of more than one type of diabetes. The absence of a well-articulated normative model and disagreements among experts provide additional sources of confusion to lay people.

In the context of the ecological model, mental models can be studied at the group or organizational/community levels as well as the individual level. From the individual perspective, research on personal models attempts to identify variables that the individual believes are central to living with diabetes (16). From the perspective of groups, some research has identified cultural variations in casual beliefs about diabetes as well as perceptions of severity (17). There is emerging evidence that people often misunderstand their own or their family member’s risk status. Certain ethnic and socioeconomic groups seem particularly vulnerable to such misunderstandings (18).

The general public and individuals with the disease may hold different mental models, with the public more conscious of acute problems (e.g., insulin shock) and those with the disease more concerned about chronic problems (19). This scenario may cause confusion regarding the seriousness of and susceptibility to diabetes or its complications.

Decision analysis
Decision analysis examines available choices and the full suite of issues that might impinge on a choice. This allows subsequent risk communication to focus on information most relevant to the available choices. Thus, for a decision about policies regarding weight loss, the decision analysis for a group living in a mild climate with easy access to healthy foods may be quite different than that for a group living in wintry isolation from a variety of fruits and vegetables.

Diabetes presents many risk management choices to affected individuals regarding lifestyle changes, type of treatment, revealing one’s health status, or insurance. Masking these decisions, onset of type 2 diabetes is often insidious so that millions remain without symptoms that might prompt diagnosis and explicit decision making.

Decisions about diabetes also include organizational decisions, such as about investments in lifestyle modification programs, and community or national policy decisions regarding screening programs, reimbursement for preventive services, regulation of the food supply, or provision of exercise resources.

Decisions in diabetes prevention draw on a common set of intellectual abilities, including understanding technical information, assessing uncertainties, anticipating one’s own future responses, and explaining one’s needs. Research compares how people perform such tasks relative to models of effective decision making. Framing decisions in terms that resonate with what people intuitively do facilitates better choices.

Risk communication
Having compiled what is known about a problem, what people believe about it, what choices are available, and what factors impinge on those choices, developing communications can begin. Risk communications may be designed to facilitate risk management at the individual, group, or community/organization levels. At the latter, policy changes or economic, social, or cultural initiatives may be considered. Key considerations include 1) whether the goal is to persuade people to behave in a particular way or to inform them of their options; 2) whether the
audience is composed of individuals, families and groups, organizations, communities, or policymakers; and 3) what forms of communication to use.

Risk communication needs to address both quantitative and qualitative components of mental models and decisions. On the one hand, individuals need accurate information about the probability and seriousness of the possible outcomes of their choices (e.g., a disease, a complication) (10,28,29). On the other hand, they need to understand the factors and processes that lead to these risks and that determine the quantitative estimates. In this area, findings of risk communication research may run counter to common sense. Conclusions stated in dogmatic or reassuring ways are not as effective as communications of clear, plausible mental models that justify those conclusions (9). When individuals understand risk estimates in the context of a coherent mental model, they feel competent acting on their beliefs as well as making sense of competing claims (e.g., in the news media, from friends). Insufficient confidence can lead to paralysis, when action is needed (26). But undue confidence can lead to ill-advised choices, when additional guidance should be sought.

Recommendation
Research should examine risk perception and decision making in individuals at risk of diabetes. Such research into their mental models needs to be framed by empirical models of key elements of diabetes risk, including policy analysis and judgments of seriousness, susceptibility, and treatment efficacy. Fundamental as well as applied behavioral research should elucidate how people comprehend and make wise decisions regarding the complexities of diabetes prevention. All of this may be facilitated by application to diabetes of research on risk communication in other areas of health and disease.

SCREENING FOR DIABETES

Screening recommendations
Screening for type 1 diabetes outside of well-defined research protocols is not recommended by the American Diabetes Association (ADA) because it is not clear what action should be taken if an at-risk individual is identified, the yield would be small because of low incidence, and some tests lack clear cutoff points (20).

Although we know that type 1 diabetes is a genetic and autoimmune disorder, the etiology of the disease remains unclear. Even among monozygotic twins, the concordance rate for type 1 diabetes is <50% (30). It is now believed that environmental factors trigger the autoimmune process in genetically at-risk individuals. Suspected environmental triggers range from purely biological (specific viruses) to behavioral (infant stress) (31). Behavioral science has an important role in determining behavioral and psychological triggers in the etiology of diabetes.

Although population screening for type 1 diabetes is not recommended, screening has an important role in studying individuals at risk to understand the natural history of the disease. Recognizing type 1 diabetes as an autoimmune disease led to screening programs to identify individuals with islet cell antibodies, indicating that the autoimmune process was underway (32,33). However, the trigger for the autoimmune process remains unknown. Consequently, genetic testing is currently being used to identify at-risk infants before inception of autoimmunity (34). Improved understanding of the pathogenesis of type 1 diabetes would offer hope of leading to effective preventive interventions.

For type 2 diabetes, the ADA (6,20) recommends that screening be performed within health care settings rather than community settings, which usually lack organized resources for follow-up of positive screening results. There are several options for type 2 diabetes screening. Fasting plasma glucose (FPG) is easier, more acceptable to screening candidates, and less expensive than, for example, the oral glucose tolerance test (OGTT). The OGTT is often used to follow up an abnormal or suspicious FPG. Other potential screening tests, such as HbA1c, are not currently recommended for diabetes screening.

Psychological factors in screening
Identification as "at risk" for type 1 diabetes is associated with psychological distress for both the individual at risk and for family members (35–37). Although initial distress tends to dissipate over time, some individuals remain anxious some months after at-risk notification. Certain coping styles have been associated with persistence of anxiety (38). Screening of children raises concerns about the impact of at-risk identification on self-perceptions, social interactions in the developing child, and access to care. These risks are part of the reasoning behind recommendations that screening for type 1 diabetes be limited to well-defined research protocols (20).

Screening for type 2 diabetes appears to have varied effects: reassurance for some individuals and heightened anxiety for others. One study failed to show a rise in anxiety in a group of relatives of people with type 2 diabetes who themselves were being screened for the disease (39). In this study, people who reported prior treatment for anxiety or depression were more likely to be anxious after screening. Experiences with and reactions to screening may also vary by age and ethnicity (40). Little research has addressed the best methods for providing support or assistance during this process.

Recommendation
Research on psychological, behavioral, and social impacts of at-risk notification would inform further research on the best methods to communicate at-risk status and to help individuals and families cope with at-risk notification. Both early identification programs and research to improve them would benefit from research on psychological factors related to subject recruitment and retention in natural history and prevention trials. Reflecting the reciprocal nature of research in all of these areas, research on behavioral or psychological factors in disease etiology may expand the base of knowledge for identification of those at risk.

LIFESTYLE AND MEDICATION IN PREVENTION OF TYPE 2 DIABETES — Recent studies in China (2), Finland (3), and the U.S. have demonstrated that diabetes can be prevented. The DPP (1) evaluated lifestyle intervention and metformin in preventing diabetes in 3,234 adults between the ages of 25 and 85 years and with IGT, treated in 27 centers throughout the U.S. The lifestyle intervention focused on loss of 7% of body weight and on achieving 150 min physical activity each week. The intervention was administered by an individual coach through a series of 16 sessions during the first 24 weeks of the program. These sessions were followed by individ-
ual contact at least monthly and face-to-face contact at least bimonthly for the balance of the DPP. The intervention included behavioral management procedures, such as goal setting, identification of concrete changes, and identification of plans for coping with temptations for relapse, all implemented in a highly individualized manner (41).

The DPP also included a double-blinded placebo-controlled test of metformin, a medication long used in the management of type 2 diabetes. The metformin and placebo groups also received encouragement to lose weight and exercise, repeated yearly but without individualized discussion of how to achieve these goals (41).

The results of the DPP were extremely encouraging. Relative to placebo, the lifestyle intervention reduced the incidence of diabetes by 58%, and metformin reduced the incidence by 31%. Countering expectations that “old dogs” cannot learn “new tricks,” the lifestyle intervention reduced the incidence of diabetes by 71% among those 60 years of age or older, a group at heightened risk and burden, in contrast to a 58% reduction for the entire age range (1).

The results of the DPP illustrate how decision analysis can depend on the ecological level at which risks are considered. Aggregated over an entire population, the difference between the lifestyle intervention and metformin arms (58 vs. 31% reduction in incidence of diabetes among high-risk individuals receiving a lifestyle intervention (3). A kind of dose/response analysis identified an additive benefit of each of five changes emphasized: fiber consumption, fruit and vegetable consumption, reduced dietary fat, exercise, and weight loss. The more targets that participants were able to meet, the lower their likelihood of converting to diabetes.

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PREVENTION THROUGH LIFESTYLE CHANGES

The results of the DPP point toward the importance of research on weight loss, dietary change, and physical activity. Reviewing the entirety of this literature is not possible within the confines of this article. Fortunately, recent comprehensive reviews address each. A 1998 report on overweight and obesity of the National Heart, Lung, and Blood Institute (NHLBI) and the NIDDK concluded that “a combined intervention of behavior therapy (such as stimulus control, problem solving), and LCD (low-calorie diet), and increased physical activity provides the most successful therapy for weight loss and weight maintenance” (42). The report recommended pharmacological agents only for individuals with a BMI \( \geq 30 \text{ kg/m}^2 \) or, if other medical conditions indicate urgency of weight loss, between 27 and 30 kg/m².

Promotion of physical activity has recently been reviewed by the Task Force on Community Preventive Services organized by the Centers for Disease Control and Prevention (43), and promotion of a healthy diet is the focus of a recent review of the Agency for Healthcare Research and Quality (AHRQ) (44). In addition to the endorsement of behavior therapy and behavior change strategies of the NHLBI/NIDDK obesity report, both of these reports also conclude that effective program characteristics include comprehensively addressing behavior change through as many channels and levels (individual, group, community) as possible and sustaining interventions over as long a period as possible.

A recent article from another of the panels of the November 1999 Conference on Behavioral Science Research in Diabetes reported on weight loss with clinical populations or in relatively intensive interventions delivered to individuals or through small groups (45). Complementing that article, the AHRQ report on dietary change focused on interventions directed toward general populations. The following paragraphs summarize findings of this AHRQ Diet Report, supplemented by selected additional citations. This summary should provide a sampling of characteristics of successful programs for lifestyle change at the individual, organizational, and community levels.

INTERVENTIONS DIRECTED TOWARD INDIVIDUALS

The lifestyle intervention in the DPP was administered primarily one-on-one and in a highly individualized and flexible manner. The average weight loss in the first year of the intervention approximated the target of 7% body weight, or \( \sim 15 \text{ lbs} \) (41). Across the several years of the DPP, a sustained weight loss totaling 5% of body weight was achieved.

As documented in the AHRQ Diet Report, most dietary interventions directed to individuals have focused on dietary fat with lesser emphasis on fiber, fruits, and vegetables or weight loss. Most have been implemented through health care settings. Strategies that have achieved significant reductions in fat intake have included group counseling; inclusion of family and spouses; focus on behavioral approaches such as self-monitoring, problem solving, and relapse prevention (46, 47); emphasis on individualizing interventions according to stages of change (48–50); and use of computer or interactive video components (51).

INTERVENTIONS THROUGH ORGANIZATIONS

In general, school-based interventions that have been successful have focused on multiple levels of intervention, including classroom instruction by teachers, environmental changes such as cafeteria food choices, and family involvement through dietary-related homework, activity packets, or group meetings (52–54). The CATCH (Child and Adolescent Trial for Cardiovascular Health) trial demonstrated that altering school lunch and physical education environments can influence dietary behaviors of children (55–57).

Organizational settings have also included work sites. Successful programs most often used multiple strategies across multiple levels, such as including workers’ families (58) or environmental changes such as increasing availability of healthy food choices (59). Tactics in successful programs include the following: screenings, nutrition classes, goal setting, changes in food available through cafeterias and vending machines, individualized feedback on food intake, mailed self-help materials, family components, and participatory approaches such as employee advisory boards to help plan interventions (58–60). Focusing on naturally occurring groups, one successful work...
Successful programs have included atten-

cial cliques of blue-collar employees (61).

Interventions at the community level.

mal cliques of blue-collar employees (61).

resulted were impressive. Among individuals

taking the drug, 72% took ≥80% of pre-
scribed medication. Among those taking

others. The full dose of 850 mg metformin

are, whereas the remaining 16% presumably

Poor adherence to preventive and

medication to prevent chronic disease. Research in adherence is

complicated by reporting biases and er-

ers in measurement of pill taking (78).

Problems specific to adherence to preventive medications include absence of symptoms that might prompt pill taking, uncertainty about the need for the medication (especially when there are no symptoms for it to relieve), and barriers related to health beliefs for preventive versus therapeutic remedies. These problems underscore the earlier discussion of the importance of a clear mental model of risk as a basis for risk communication and decisions among alternative actions.

Other risky behaviors

Many behaviors other than those consid-

ered here contribute to disease burden among people with diabetes. For exam-

ple, smoking is not a risk factor for diabe-

tes, but the synergy of smoking and diabetes entails as much as a 12-fold in-

crease in cardiovascular risk (79). Com-

prehensive efforts to prevent diabetes should include attention to smoking and

other behavior patterns such as stress or depression (80), which are often associ-

ated with diabetes and add to its burden.

Recommendation

A major priority is translation of DPP findings that type 2 diabetes can be pre-

vented. This will benefit from progress in risk communication, early identification of those at risk, and participatory research addressing cultural, social, and community factors in diabetes prevention. Re-

search should examine strengths and

limitations of informal community chan-

nels and participatory approaches, formal professional channels, and technological approaches (e.g., computer-based tai-

lored communications) to population-

based health communication and prevention. In addition to diet, weight, and physical activity, prevention research

should include smoking and other behav-

iors that contribute to the disease burden of diabetes.

Research on mental models and decisions about taking preventive medications should facilitate translation of the DPP’s positive results with metformin. With this as a background, research should examine risk communications and multiple brief behavioral interven-

tions from the DPP to promote use of and adherence to medications for diabetes prevention.

SOCIOCULTURAL

DISPARITIES — Diabetes is sharply stratified by socioeconomic disparities, with heightened prevalence and burden among people of color and those who are educationally or economically disadvan-

taged (81–83). Thus, an important fea-

ture of the DPP was its inclusion of African-Americans, American Indians, Asian Americans, and Hispanics and Lati-

nos who, together, made up 45% of par-

ticipants—more than in any other major clinical or prevention trial. Most impres-

sive, the striking benefits of lifestyle inter-

vention and metformin did not differ either among or between the minority groups and the other 55% of participants (1).

Two key observations about reaching disadvantaged minorities are that they are relatively isolated from formal or main-

stream channels of information and that they use informal sources of information (84). Both observations suggest peer-

based and community programs that will enlist informal social networks to disem-

inate health messages and provide peer and informal support for behavior change (85).
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One approach to this is to implement programs through existing networks of intended audiences. For example, Stolley and Fitzgibbon (86) implemented an intervention promoting low-fat diet through a tutoring program for low-income mothers and daughters. Similarly, Hispanic families were reached through literacy training programs (62). Church-based approaches have been popular in efforts to reach African-Americans. A church- and community-based program promoted healthy eating through lay health advisors, pastor support, community coalitions, and distribution of materials through local grocers (87). In Samoa, a church-based program used a participatory approach and was successful in reducing waist circumference and eliminating weight gain among those at high risk for diabetes (88).

Recommendation
Research should examine how risk perception and communication, early identification, and prevention are influenced by group and cultural differences and social and economic factors associated with disproportionate diabetes burden. Research to reduce disproportionate diabetes burden should include participatory approaches to interventions.

GENERAL THEMES AND CONCLUSIONS — Progress in any one of risk communication, early detection, and prevention creates opportunities for progress in each of the other areas. For example, better understanding of diabetes and approaches to early detection identify new topics for risk communication and prevention. At the same time, improved prevention programs increase the range of alternatives for risk communication to address and increase the potential benefits of early detection. Similarly, better approaches to risk communication may increase the numbers interested in early identification and prevention. Finally, all of these will be enhanced by better understanding of the etiology of diabetes.

Fundamental research
Cutting across all the topics addressed is the utility of fundamental research to increase understanding of how people recognize and appraise risks; how they respond to early identification of their own risks; how to encourage healthy diet, weight loss, exercise, and appropriate use of medications; and how all of these may be influenced by social and cultural differences.

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