

Report of the Health Care Delivery Work Group

Behavioral research related to the establishment of a chronic disease model for diabetes care

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As one of four work groups for the November 1999 conference on Behavioral Science Research in Diabetes, sponsored by the National Institute on Diabetes and Digestive and Kidney Diseases, the health care delivery work group evaluated the status of research on quality of care, patient-provider interactions, and health care systems' innovations related to improved diabetes outcomes. In addition, we made recommendations for future research. In this article, which was developed and modified at the November conference by experts in health care delivery, diabetes and behavioral science, we summarize the literature on patient-provider interactions, diabetes care and self-management support among underserved and minority populations, and implementation of chronic care management systems for diabetes. We conclude that, although the quality of care provided to the vast majority of diabetic patients is problematic, this is principally not the fault of either individual patients or health care professionals. Rather, it is a systems issue emanating from the acute illness model of care, which still predominates. Examples of proactive population-based chronic care management programs incorporating behavioral principles are discussed. The article concludes by identifying barriers to the establishment of a chronic care model (e.g., lack of supportive policies, understanding of population-based management, and information systems) and priorities for future research in this area needed to overcome these barriers.

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The planning committee for the Behavioral Research and Diabetes Conference held 18–19 November 1999 on the National Institutes of Health campus created four “virtual work groups” to organize and present sessions at the conference. The purpose of the conference was to summarize the current status of behavioral science research in diabetes and related areas and to make recommendations for

future research. This work group report covers behavioral science research in diabetes as applied to the U.S. health care delivery system for diabetes. Each work group was charged with summarizing the pertinent literature and presenting recommendations concerning the following: 1) key advances that have been made, 2) barriers to progress, and 3) recommended research priorities.

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Abbreviations: NIDDK, National Institute of Diabetes and Digestive and Kidney Diseases.

A table elsewhere in this issue shows conventional and Système International (SI) units and conversion factors for many substances.

The Health Care Delivery System work group was the only one explicitly charged with considering issues beyond the level of individual patient and provider behaviors. This report focuses on health care delivery research, because it is the subset of the broader social context (e.g., community, work place, and policy factors) in which the greatest amount of research has been conducted in diabetes, and one that is clearly within the scope of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). In making this decision, we recognized that there are currently gaps between the types of research that NIDDK has historically funded and those that are considered “translation” or health services research and sometimes funded by other agencies.

Importance of patient-provider and health systems research

There were several reasons for selecting patient-provider and health systems research as one of the four areas of behavioral science research to be reviewed and discussed at the conference. First, there is increasing evidence that good self-management is related to improved diabetes outcomes (1–5). Comprehensive reviews have demonstrated the importance of lifestyle behaviors such as physical activity (6–8), healthful eating patterns (9–11), and smoking cessation (12) to both diabetes-specific and general health outcomes.

Second, positive patient-provider interactions and satisfaction with medical care are important determinants of patient self-management (13–16) and can either support or undermine patient self-management efforts (17–19). Several studies have demonstrated that among various recommended diabetes best-care practices and performance measures, those related to support of self-management appear to be conducted least often (20,21). When this knowledge is combined with the fact that most providers are being asked to do more and more, during shorter and shorter office visits, the need for different ways of delivering diabetes care is clear.

The positive news is that new models of how to effectively deliver care for diabetes and other chronic illnesses have been identified and validated (22–27).

In consideration of the above-mentioned issues, the goal of the work group became to establish a chronic disease model as the norm for diabetes care in this country. The key advances described in the next section can be applied to the vast majority of diabetic patients only if such a delivery system exists. The barriers noted in the section that follows describe impediments to achieving that goal, and the final section on recommended research priorities denotes the key steps that must be taken to reach that goal.

KEY ADVANCES — The work group considered both diabetes-specific and related research on other chronic illnesses. The purpose of the summaries below is to highlight key findings from behavioral science research related to health care delivery. We have organized this summary of key advances into three areas that the review group judged most important to successful diabetes management: research on patient-provider interactions, reaching underserved and minority populations, and efforts to establish a chronic care model. More comprehensive reviews are available both of this general area (28–31) and specific topics (cited below).

Patient-provider interactions

A great deal has been learned about patient-provider interactions, including the types of interactions that result in greater patient satisfaction and higher levels of self-management. Two conceptual issues are important to emphasize before discussing more specific findings. First, although health care providers can provide helpful (and sometimes less helpful) recommendations, advice, and counseling, it is the patient who must decide which strategies to put into practice and experience the consequences—both positive and negative—of self-care actions. Patients and their families, not health care professionals, are responsible for the management of their diabetes (17,32–34). There is abundant evidence that patients can and do change regimen recommendations after leaving the medical office (35). Thus, it makes sense to develop collaborative plans and management goals with patients rather than to prescribe regimens to which patients are expected to adhere. This fundamental

change in provider approach greatly increases the communication between parties and the likelihood that patients will succeed. This change in being responsible to patients—rather than responsible for patient self-care—is in contrast to the acute-care and short-term-focused models of medical management in which most providers and educators have been trained. This shift in view, from the provider to the patient being the most active decision-maker and problem-solver, is central to productive patient-provider interactions for management of diabetes and other chronic illnesses (22,36–38). Second, for these reasons, as well as methodological issues (39,40), the terms “diabetes self-management” and “self-management education” rather than “adherence/compliance” and “patient education” are preferred (17,41).

Both diabetes-specific research and general medical research on patient-provider interactions have consistently found that interactions that are focused around patient concerns and in which the patient is listened to and helped to work through issues result in greater patient satisfaction than do provider-centric interactions in which the provider does almost all of the talking and gives directions (14,16,19,42,43). Patients who feel understood and supported by their providers are more likely to have high levels of self-confidence and to succeed at behavior change (44). In addition, improved patient-provider communication and increased involvement of patients in decision-making are associated with improved behavioral, biological, and quality-of-life outcomes (5,18,45). Training and intervention approaches, such as motivational interviewing and empowerment training, have been developed and validated to give health professionals experience in this type of interviewing and counseling (46,47).

Another finding that has been replicated in several meta-analyses and literature reviews (1,2,48) is that knowledge alone is insufficient to produce behavior change. This finding has had a major impact on diabetes self-management training and has been influential in prompting patient education to become more behavioral and outcomes oriented (e.g., tracking improvement in self-management behaviors, biological measures, and quality of life) rather than content oriented, and to focus on problem-solving and coping strategies rather than didactic education (49).

Modern diabetes self-management education is effective in producing both behav-

ioral and biological improvements (2,30,50). Economic and quality-of-life outcomes of self-management education and patient counseling have been studied less often, although there are encouraging studies in these areas as well (3,51). A final finding regarding patient-provider interaction is that it is important to tailor intervention plans to patient needs, preferences, and social environments (52–54).

Reach to underserved and minority populations

Traditional approaches to diabetes education and self-management support have been less effective at reaching and helping the most vulnerable segments of the diabetes population (55–58). Many individuals with type 2 diabetes have never received any patient education (51,59,60). Of even greater concern is that those who are older, are of lower socioeconomic and education levels, and are members of minority groups are the least likely to have received diabetes education. Among the reasons for these disparities is that of the many personal, logistical, social, and economic barriers to both recommended self-management practices and to participation in diabetes education that have been identified (61–63), almost all are greater among minority groups (56–58,62–64).

There is some good news in light of the sobering data above. It has been shown that appropriately designed and developmentally and culturally appropriate programs are capable of reaching and assisting older adults and lower-income populations (62). There is also innovative work underway with African-American (58,65), Latino (66–68), and Native American populations (69,70). For many years, the burden of diabetes has been highest among minority populations, and these groups have had very limited access to diabetes self-management resources or support. Fortunately, this situation is changing. Major national and other large-scale programs are now addressing minority involvement as key objectives (71–74); this change is important, because the majority of the projected number of new cases of diabetes and the increased burden of diabetes in the coming decades are expected to be in minority populations (75,76).

Steps toward a chronic care model for diabetes

Although not widely implemented as of the year 2000, a set of principles for effective chronic illness care is emerging (22,24,31,37,77–80). These principles

Table 1—Key characteristics of effective diabetes management programs

1. Use a population-based systems approach (22,26,27,78,82).
2. Involve proactive contacts, surveillance, and reminders (24,25,82).
3. Incorporate the patient as an active participant and use patient-centered collaborative goal setting (19,22,44).
4. Implement consistent follow-up procedures (37,84).
5. Assign large responsibilities to nonphysician team members, such as nurse care managers (26,27,85).
6. Plan office visits and focus on outcomes and outcomes-related processes (22,25,27).
7. Use clinical information systems, such as diabetes registries and electronic medical records, to improve quality of care (30,86,87).

appear to be consistent across diabetes and other chronic illnesses, which is encouraging, because the majority of adults with diabetes also have comorbid illnesses. From the evaluations conducted to date (23,25–27,81), there is also reason to anticipate that these new approaches to care may be applicable to entire populations rather than just highly motivated individuals who have the time, resources, and commitment to participate in traditional diabetes education programs.

Key characteristics of these interventions are discussed below and summarized in Table 1. First, these interventions are systems based and focused on entire defined population groups (e.g., all members of a health maintenance organization or a community having diabetes) (27,72,78,81). They do not rely on individual providers or educators to remember to do things correctly, but create an environment that supports and reinforces self-management and guidelines for concordant care, rather than creating obstacles to these objectives. Second, these programs are proactive and provide prompts, reminders, and cues for both patients and health care professionals (24,25,82). Successful programs also provide consistent follow-up support so that goals, or even patients, are not lost (37,83,84).

Almost all successful chronic care programs also involve other characteristics. In their approach to patient-provider interactions, such programs involve the patient as an active team member and stress patient-centered collaborative goal setting (18,22). Second, they establish a set of guidelines or care responsibilities for the entire team and distribute these responsibilities across team members, rather than relying on primary care physicians to provide the vast majority of services (27,85). In particular, almost all successful large-scale programs to date have

involved nurse care managers as the central (of the health care professionals involved) team member (26,27,83). Third, successful programs change the way in which chronic care is conducted. Interactive contacts (e.g., visits and calls) are planned and designed to focus on needed support, outcomes, and outcomes-related processes (37).

Finally, to be successful with all patients, it is necessary to have a clinical information system that supports and integrates the above-listed activities. This system involves a diabetes registry, which is usually computerized and used to inform and prompt care. In the future, we can expect to see even more creative uses of interactive technology to enhance both patient self-management and provider actions (30,86,87).

Summary and need for research on the chronic care model

A great deal of progress has been made and important lessons learned regarding behavioral aspects of diabetes health care delivery. Progress has been made at the individual level, the patient-provider interaction level,

and the health care system level. The challenge now is to put these findings into practice. Research is needed that investigates the reach and applicability of the interventions discussed in the preceding section (88,89), especially to minority populations. Although serious deficiencies in both levels of patient self-management and delivery of quality care have been identified, this is seldom the fault of individual patients or health professionals. Rather, it is a systems issue, which must be addressed at that level (79,82).

On the basis of the above-listed findings, our work group recommends that the overarching goal for behavioral research in the diabetes patient-provider and health care delivery area be to investigate ways to establish a chronic disease model of diabetes as the norm in the U.S.

WHAT ARE THE BARRIERS TO PROGRESS?

— The priority list of barriers to establishing a chronic disease model as the norm for diabetes health care is presented in Table 2. This listing, and its prioritization, was accomplished by using a modified version of the nominal group process (90). Work group members submitted a total of 37 barriers to achieving the overall goal of establishing a chronic disease model for diabetes care. Members voted and the product, a rank-ordered list of the seven top-rated barriers to the work group's goal, is given in Table 2.

Many of those barriers reflect the underlying issue that the vast majority of physicians has been trained, and most of our health care systems have been established, to treat acute illness. These barriers exist, as can be seen, at the individual, practice, health system, and societal level. It is vitally impor-

Table 2—Barriers to establishing a chronic disease model for diabetes care in the U.S.

Lack of (and need for research on ways to improve):

1. Availability and understanding of population-based chronic disease management.
2. Funding or research on real-world/practice-oriented issues, systems, and organizational change strategies (to be able to translate studies to primary care settings).
3. Appropriate health care policies to provide reimbursement for—and incentives to create—a chronic disease model.
4. Systems-based support for the primary care physician's (or other staff's) implementation of behavior change strategies.
5. Understanding of the personal and social-environmental factors that lead to long-term sustained self-directed behavior change.
6. Adequate integrated information systems and sharing of information across provider groups.
7. Adequate time to address patient-focused issues in an interactive, personally tailored manner during office visits.

Table 3—Recommended research priorities in the area of health care delivery

1. Research on optimal ways to collaboratively manage chronic disease, in which the diabetes nurse specialist plays a prominent role, that is population-based and includes home-based lifestyle and psychosocial interventions. For example:
 - Studies on how to integrate self-management support and medical nutrition therapy into nurse-based case management.
 - Evaluation of different modalities and schedules of follow-up contact to support home-based interventions.
2. Evaluations of behavioral assessment and intervention methodologies that take advantage of technological advances to effect systems changes (health care team, organizations, communities). For example:
 - Testing of methods to rapidly assess and provide immediate feedback to both patients and providers that can link information on self-management, diabetes control, and patient needs and preferences.
 - Evaluation of the impact and cost-effectiveness of different patient and health care team feedback/incentive systems on quality of care.
3. Investigation of ways to augment the support system surrounding the primary care physician so that a proactive patient-focused team-managed chronic disease model can be available for all patients with diabetes. For example:
 - Research on the Internet and other interactive technologies to inform patient-provider interactions, deliver self-management support, and coordinate health care team efforts.
 - Comparisons of diabetes-specific versus general chronic disease management interventions.

tant to conduct research that addresses these barriers. We must evaluate different programs, structures, and policies that have the potential to overcome these impediments to implementation of a chronic disease model.

In the long-term, undergraduate, graduate, and continuing education of health care professionals in population-based and public health approaches to chronic illness care (37,91–93) is needed, as are changes in reimbursement and incentives for provision of preventive care, diabetes self-management, and follow-up contacts. In the near term, several of the barriers in Table 2 could be addressed by targeted research to identify practical broadly applicable organization strategies to enhance delivery of planned proactive care and on optimal methods of tailoring interventions based on social-environmental and cultural factors. In particular, greater funding is needed for diabetes research on 1) systems and organizational change research and 2) ways to integrate information systems with behavioral interventions. Many of the barriers in Table 2—and the types of research needed to address these barriers—cut across areas traditionally funded by the NIDDK, the Agency for Healthcare Research and Quality, the Centers for Disease Control and Prevention, and private foundations. Others fall into a gap and are not funded by any of these agencies.

None of the problems mentioned above can be remedied by minor changes

or add-ons to the current acute-care model of health care. Rather, a fundamentally different approach is needed to provide quality care for patients with diabetes and other chronic illness. The following section outlines research that will help to produce such a chronic illness model.

RECOMMENDED RESEARCH PRIORITIES

— At the completion of the group's discussions, 28 ideas for recommended research priorities were assembled and sent to the work group members to prioritize. The procedure was the same as that described previously in the barriers section. Table 3 lists a rank order of recommended research priorities for further behavioral research within the diabetes health care delivery sphere. These three overall recommendations were presented at the November conference and modified based on the ensuing discussion. Under each of the three summary recommendations, we have provided examples to illustrate the types of studies that emerged as highest priority from our work group and interactions at the larger meeting.

As can be seen in Table 3, there are many opportunities to apply the lessons learned in research to date. The health services sector badly needs diabetes research that is more relevant to the issues faced by practicing clinicians. Research needs to move from efficacy studies to effectiveness

and dissemination evaluations (88,94). The recent promising results from innovative delivery systems for both diabetes and other chronic illnesses (37,85,95,96) demonstrate that carefully controlled research can be conducted in real-world practice settings and can produce important outcomes. There are more opportunities than ever before to incorporate tools and resources, such as electronic diabetes registries, interactive behavioral technology, and new models of how patients and team members can work together to collaboratively address chronic illness. There is important basic research on clinical practice, organizational, and health care system change that is greatly needed and should be supported by the NIDDK.

What is needed is intervention research on the issues outlined in Table 3 that reaches and improves outcomes for large segments of the population of a clinic, health care system, community, or region (37,97) and especially those who are most in need. The scientific community and the NIDDK have the opportunity to substantially close the gap between ideal and practice and to make significant progress on reducing existing diabetes health and health care disparities and toward the goals outlined in *Healthy People 2010*. This will not happen without changing the current funding focus, however, and without devoting greater attention and funding to approaches that address the barriers in Table 2 and without investing in the research priorities in Table 3.

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