Behavioral and Psychosocial Issues in Diabetes: Summary of Proceedings of the National Conference

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An unprecedented conference was held on May 20–23, 1979, in Madison, Wisconsin. Leading diabetologists, behavioral scientists, and those who live with diabetes assembled to critically review the emotional and psychosocial problems associated with diabetes, to suggest specific approaches to address the problems, and to provide an opportunity for biomedical and behavioral scientists to exchange information and perspectives. The diverse backgrounds and expertise of the participants encouraged multifaceted views of both problems and proposed solutions.

The Conference on Behavioral and Psychosocial Issues in Diabetes was cosponsored by four NIH Institutes,* the National Institute of Mental Health, and the National Diabetes Advisory Board. Its purpose was to draw attention to the research issues and opportunities in this area. The goals of this Conference were:

- to identify existing behavioral knowledge and techniques and to suggest methods of application to the problems of diabetic individuals and their families
- to identify research areas of most need and promise
- to actively encourage the interface between biomedical and behavioral researchers and clinicians
- to attract both new and established behavioral investigators into the diabetes research area
- to develop new models and approaches for the study of adherence and outcome in diabetes

CONFERENCE STRUCTURE

To accomplish these purposes, the formal presentations to the conferees were paired to present a balanced view of both biomedical and behavioral perspectives on each topic. For example, the two presentations for the topic of compliance/adherence were "Issues in the Management of Diabetes" and "Adherence to Treatment for Diabetes". The formal presentations each morning and afternoon were immediately followed by workshops to discuss the topics in depth.

The 64 invited participants represented the diverse backgrounds and expertise of physicians, psychiatrists, and psychologists experienced in diabetes or in other chronic diseases, educators, individuals with diabetes, parents of diabetic children, nurses, clinicians, and researchers. There were six task groups with approximately 10 members each. In addition, each group had a special focus, e.g., research methodology, therapeutic strategies, coping, and predictable crises of diabetes.

RECOMMENDATIONS

From the group summary reports, seven major areas of recommendations were suggested.

1. Research. There is a need to further identify specific areas of concern in the management of diabetes; to develop appropriate research designs and to select assessment tools that can answer the questions posed; and to translate findings into pragmatic and meaningful terms that lead to clinical, medical, and psychological interventions to enhance patient care. The following are some of the potential research areas that were identified by several groups:

1. Studies are needed on the direct effects that shifting metabolic states have on moods and behaviors of diabetic persons.

2. To ameliorate the impact of crises related to the predictable course of diabetes, research is needed to identify various coping strategies and to determine their effectiveness under varying circumstances.

3. Applications of recent advances in areas of stress management need to be investigated to provide the diabetic patient with long-term, easily applicable methods of reducing tension.

4. A concerted effort needs to be made to collect and to evaluate instruments that assess the degree of patient and family behavioral adjustment.

5. The efficacy of diverse education approaches and behavioral interventions in enhancing adherence to prescribed

* National Institute of Arthritis, Metabolism, and Digestive Diseases; National Institute of Child Health and Human Development; National Heart, Lung, and Blood Institute; National Institute on Aging.

regimens, in stabilizing metabolic control, and in influencing health and psychosocial outcomes needs to be assessed.

6. Research is needed on the effects of the match between practitioner behaviors and patient characteristics on therapeutic outcomes.

7. Innovative approaches to care for the elderly diabetic person and for those living alone need to be developed and evaluated.

8. Efforts should be made to encourage the development of increased research capacity through the use of existing research training programs and by developing new ones.

2. *Therapeutic alliance.* There was a consensus that a therapeutic alliance—a multidisciplinary team of health care providers that includes the patient and, in cases of children, parents—will enhance adherence to an individualized treatment plan. Conferees noted that the busy physician seldom has the time to comprehensively educate the diabetic patient at his or her level of understanding and emotional need. A cooperative team is a key element to assure the receipt, integration, and utilization of new knowledge and emotional acceptance. Members of this team should include the patient, physician, nurse, and dietitian or nutritionist, all with designated responsibilities including individual education. Other members, such as a podiatrist, psychiatrist, psychologist, physical therapist, and pharmacist should be available as needed.

Although multidisciplinary teams are complex, the participants noted that a mix of expertise, such as that represented at the Conference, should be very productive because of the cross-fertilization of ideas from people with varied approaches. To provide more comprehensive care, the participants recommend that:

1. The concept of the team approach for diabetes management, which has been endorsed by the American Diabetes Association, also be endorsed by the other major diabetes organizations;

2. Medical and nursing schools be encouraged to integrate the alliance process in their training programs;

3. This cooperative approach to diabetes care be adopted as standard practice by professional societies and organizations and be an integral part of continuing education programs.

3. *Professional education.* Every task group emphasized the need for professional education regarding the multiple psychological and social issues associated with diabetes mellitus and other chronic illnesses. There was general agreement that the training of health care providers should highlight the need to assist patients and their families in ongoing care as well as in crisis situations. Formal courses should not only include the psychosocial aspects of diabetes, but must also teach intervention techniques and aid in developing relevant skills.

In addition, it was noted that the diabetes education specialist, usually a nurse or dietitian, is often inadequately trained in education and evaluation methods and techniques as well as in new concepts of health education. The purpose of patient education is not only to inform but to develop and sustain patient motivation to implement appropriate health behaviors. Therefore, the participants recommend that:

1. The American Association of Medical Colleges encourage medical schools to develop programs to educate students in the psychosocial aspects of diabetes and of other chronic diseases and in the roles that these factors play in influencing health behaviors and outcomes;

2. The American Association of Diabetes Educators and the American Diabetes Association continue to develop formal training programs in patient education and evaluation methods. Certification and possible licensure should be considered;

3. Regularly offered continuing medical education credit programs be developed by professional societies to emphasize the expanded role of the health care provider.

4. *Role of support systems.* All too often, living with diabetes and dealing with its related crises will surpass the diabetic person's ability to cope. The family can be an invaluable resource in dealing with the stresses of the illness and must be incorporated into the therapeutic regimen if satisfactory treatment is to be provided. Additionally, the role of the family must be supplemented by a variety of other community supports. Church, school, business, civic, and service organizations have the potential for providing additional emotional sustenance, information, education, and emergency aid. The help that is available from these various support groups needs to be explored, developed and utilized by the health team. The hospital social service department can serve as the liaison between the health care providers and community resources. It is recommended that:

1. Community mental health centers explore the potential roles of a variety of support systems and provide community resource directories to hospitals, clinics, and private health care providers.† In addition to the family, these include church, school, work, community, and social groups;

2. An appropriate federal agency convene a workshop of experts to propose a plan for identifying or developing sources of aid and to make recommendations to appropriate federal, state, and community agencies and to other groups about implementation;

3. Appropriate HEW agencies should be required to include planning for social support systems within their local and state five-year plans.

5. *A series of follow-up meetings.* To further explore issues of concern, a number of small meetings on well-defined, limited topics should be supported by appropriate HEW agencies such as HSA, HRA, HCFA,‡ NIH, and ADAMHA Institutes. Some recommendations for topics of consideration are:

1. To identify and critique existing behavioral science instruments currently used in the evaluation and comprehen-

† **This is an endorsement of the recommendation of the Task Panel on Community Support Systems,** *Task Panel Reports Submitted to the President's Commission on Mental Health,* **Vol. II Appendix, GPO Stock No. 040-000-00391-6, 1978, p. 178.**

‡ **Health Services Administration, Health Resources Administration, Health Care Financing Administration.**

sive care of individuals with other chronic diseases for possible application to the diabetic population;

2. To propose strategies for studying the effects of family interactions on health outcomes, including adherence behaviors;

3. To develop methods to enhance diet management of adult, non-insulin-dependent diabetic persons;

4. To design strategies to provide a social support network for those diabetic individuals with special dependency needs such as the elderly, those who are socially isolated, and those with incapacitating complications.

6. *Funding.* The participants of this Conference strongly recommend increased government support for professional training, to support research, to fund patient education programs, and to promote interdisciplinary conferences and exchanges related to the behavioral and psychosocial aspects of diabetes and its complications. It was recognized by the conferees that all components of the federal government responsible for any aspects of health care must participate in the support of these programs.

The federal interagency Diabetes Mellitus Coordinating Committee (DMCC) is the appropriate group to oversee the implementation of new or previously underfunded programs in member agencies, and the DMCC is urged to give priority to the following additional recommendations:

1. Patient education must be viewed as an integral part of medical therapy and, consequently, must also be adequately funded.

2. At federal, state, and local levels, Medicare and Medicaid must lead the way for reimbursement of patient education costs if commercial carriers are to follow.

3. The National Diabetes Information Clearinghouse should review the sources of available state support money, categorical and general, for handicapped individuals. The results of this review should be published and kept current as a directory for funding resources.

7. *Developing new perspectives.* The practicing health care professional must be made sensitive to and become educated about the emotional, psychological, and social issues associated with diabetes. Efforts must be made at both the patient and the professional levels. To achieve this, several specific actions were recommended by the Conference participants, including:

1. A report of the discussions held at this Conference should be widely publicized in lay magazines as well as in professional journals.

2. A Consumer's Guide to Comprehensive Diabetic Care should be developed, endorsed, and widely disseminated by the American Diabetes Association, the Juvenile Diabetes Foundation, and the American Association of Diabetes Educators.

3. Efforts should be made by diabetologists and by diabetes organizations to encourage leading community representatives to become more involved in speaking about these issues at meetings and with their collegues. It is anticipated that such efforts will encourage the health care community to become more knowledgeable about and to employ those interventions and techniques that are now available.

A publication, including the full proceedings of the National Conference on Behavioral and Psychosocial Issues in Diabetes, is available. To obtain the Proceedings, send a self-addressed mailing label to: Diabetes Program–Behavioral Conference Proceedings, NIH-NIAMDD, Westwood Building, Room 628, Bethesda, Maryland 20205.

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