

Psychosocial Therapies in Diabetes

Report of the Psychosocial Therapies Working Group

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OBJECTIVE — To review key advances in the behavioral science literature related to psychosocial issues and therapies for persons with diabetes, to discuss barriers to research progress, and to make recommendations for future research.

RESEARCH DESIGN AND METHODS — Key findings from the literature on psychosocial research in diabetes are reviewed separately for children and adults. Specific issues covered include psychosocial adjustment and psychiatric disorders, neurocognitive functioning, quality of life, and psychosocial therapies. Barriers that must be addressed to allow research in this area to progress are discussed. Recommendations are then made concerning high-priority areas for advancing research in the field.

CONCLUSIONS — A substantial amount of behavioral science research has demonstrated that psychosocial factors play an integral role in the management of diabetes in both children and adults. Research has also shown the efficacy of a number of psychosocial therapies that can improve regimen adherence, glycemic control, psychosocial functioning, and quality of life. More research in this area is needed to develop psychosocial intervention programs for specific patient populations and to demonstrate the cost-effectiveness of these approaches.

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This study presents the summary and recommendations of the Psychosocial Therapies Working Group, originally presented at the conference on Behavioral Science Research in Diabetes, held in November 1999, at the National Institutes of Health. In this study, we first highlight the significance of psychosocial issues in diabetes care and key advances in the field separately for children, adolescents, and adults. This review of the literature in this area is not intended to be detailed and comprehensive; several other literature reviews of behavioral and psychosocial research in diabetes have been published in recent years (1–4). Our

objective is to provide examples of key findings from the field of behavioral research addressing psychosocial issues and therapies. We then discuss barriers to research progress and conclude with specific recommendations for future research.

CHILDREN AND ADOLESCENTS

Significance

The incidence of type 1 diabetes in young children has increased in recent years (5,6). In addition, the incidence of type 2 diabetes has been increasingly recognized in older children and adolescents, often in

association with obesity (7). Large numbers of children are currently affected by diabetes, and many more will be affected by diabetes in the future.

Diabetes imposes considerable demands on children and their families. Because they are coping with normal developmental challenges, the additional burden of diabetes may be difficult for many children to deal with effectively. Especially burdensome may be the demands of intensive management. With children as patients, families play a significant role in diabetes management and are instrumental in the implementation of interventions. Diabetes can adversely affect both psychosocial and neurocognitive functioning, thus potentially affecting the quality of life of the child and the entire family. Psychosocial factors can also influence regimen adherence and glycemic control. Therefore, psychosocial factors are very important to consider in the management of children and adolescents with diabetes.

Key findings

Psychosocial functioning. Research indicates that type 1 diabetes is a risk factor for the development of psychiatric disorders in children and adolescents. Many children have adjustment problems soon after the diagnosis of diabetes (8,9). Although most children resolve these problems within the first year, children who do not are at risk for poor adaptation to diabetes, including regimen adherence problems, poor metabolic control, and continued psychosocial difficulties (10–12). In addition, many mothers of newly diagnosed children are at risk for adjustment problems of their own, with significant depressive symptoms observed in approximately one third of mothers; most of these abate within the first year after their child's diagnosis (13).

A study of adolescents with diabetes found that one third had psychiatric disorders, most involving internalizing symptoms (14); other studies have shown that diabetic youth have greater rates of depression (15) and that those with depression have poor glycemic control (16).

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

A 10-year longitudinal study found that nearly half of the study sample had a psychiatric diagnosis, the most frequent of which was depression (17). Another 10-year longitudinal study found lower self-esteem among young adults with diabetes (18). Poorer psychological adjustment during adolescence may persist into adulthood (19).

Research has also shown that diabetic youth, particularly adolescent girls, are at increased risk for eating disorders. Both eating disorders and subclinically disordered eating attitudes and behaviors (e.g., severe dietary indiscretion and repeated insulin omissions) have been observed in adolescent girls with diabetes and are associated with worse metabolic control (20,21). At least 10% of adolescent girls with type 1 diabetes meet diagnostic criteria for an eating disorder, a rate twice as high as in girls without diabetes (21). Without intervention, disordered eating and insulin manipulation may worsen over time and increase the risk of health complications (22).

Neurocognitive functioning. Studies indicate that children who develop diabetes before 5 years of age and/or who have frequent episodes of hypoglycemia are at risk for neurocognitive deficits, particularly in visual-spatial functioning (23–25). In addition, research findings indicate that children with diabetes miss more school than peers without diabetes and that lower reading achievement was related to more school absences (26). Studies have also shown that diabetic children, especially boys, are more likely to have learning problems (27).

Other research has found poorer attentional functioning and lower verbal intelligence in children with a history of significant hypoglycemia (28). A longitudinal study of newly diagnosed children revealed declines in verbal intelligence and school grades, predicted in part by memory dysfunction (29,30). Another study showed that 2 years after diagnosis, children exhibited mild neuropsychological deficits, including reduced speed of information processing, and decrements in conceptual reasoning and acquisition of new knowledge (31), which were predicted by both recurrent hypoglycemia and hyperglycemia, as well as early onset of diabetes (before 5 years of age) (32).

Quality of life. Relatively few studies have specifically examined quality of life in children and adolescents with diabetes

(33). Quality of life in individuals with diabetes can be reliably measured by self-report (34). Research findings indicate that better quality of life in youths is associated with increased self-efficacy and less depression (35), as well as improved metabolic control (36).

Psychosocial factors related to regimen adherence and metabolic control. Research has shown that regimen adherence declines over time and is especially poor among some adolescents (37,38). Metabolic control has been noted to be worse in single-parent, lower-income, African-American youths (39–41).

Family factors are significantly associated with regimen adherence and metabolic control in children and adolescents. For example, low levels of family conflict and stress, high levels of cohesion and organization, good communication skills, and appropriate involvement of both parents and children in diabetes management have been associated with higher levels of regimen adherence (42,43) and better metabolic control (44–47). When parents allow adolescents to have self-care autonomy without sufficient cognitive and social maturity, they are likely to have more problems with diabetes management (48,49).

Research has also examined the role of stress and coping in relation to diabetes management. Children who have less life stress (46) and who cope well with diabetes management are more likely to have fewer problems with regimen adherence (50) and metabolic control (51).

Adolescents' health beliefs are related to their regimen adherence and glycemic control. In particular, high levels of self-efficacy (52) and low levels of learned helplessness (53) have been associated with good glycemic control. Specific health beliefs related to the seriousness of diabetes, personal vulnerability to complications, costs of regimen adherence, and beliefs in the efficacy of treatment have also been associated with both regimen adherence and glycemic control (54). Similarly, studies with younger children have shown that their health beliefs are related with adherence and glycemic control (55).

Psychosocial therapies. A number of controlled studies have examined the efficacy of psychosocial interventions for diabetic youth. Most of these have included the family as an integral part of treatment. Research findings indicate that

family-based behavioral procedures such as goal-setting, self-monitoring, positive reinforcement, behavioral contracts, supportive parental communications, and appropriately shared responsibility for diabetes management have improved regimen adherence and glycemic control (56,57). In addition, such interventions can improve the parent-adolescent relationship (56,58). Psychoeducational interventions with children and their families that promote problem-solving skills and increase parental support early in the disease course have improved long-term glycemic control of children (59).

The efficacy of group interventions for diabetic youth has also been systematically evaluated. For example, research findings have shown that peer group support and problem-solving have improved short-term glycemic control (60,61). Group coping skills training has been shown to help optimize glycemic control and quality of life for adolescents involved in intensive insulin regimens (62,63). In addition, stress management and coping skills training has reduced diabetes-related stress (64) and improved social interaction (65) in adolescents.

ADULTS

Significance

Diabetes is a psychologically and behaviorally demanding disease; therefore, psychosocial factors are relevant to nearly all aspects of its management. The psychosocial impact of diabetes has been recognized as a stronger predictor of mortality in diabetic patients than many clinical and physiological variables (66). Considering the importance of psychosocial factors in management of diabetes, the rapidly increasing number of adult patients with diabetes (mostly type 2), and the tremendous and growing public health burden of diabetes, the development and clinical implementation of effective psychosocial interventions are critical needs. Such interventions could help patients improve self-care behaviors and glycemic control, thus reducing their risk of health complications and improving their quality of life.

Key findings

Psychosocial functioning. Substantial literature documents the prevalence and course of psychiatric disorders, particularly affective and anxiety disorders, in

adults with diabetes (3). Research findings have demonstrated that depression is more common in patients with diabetes than in the general population; at least 15% of patients have clinical depression (67,68). Findings indicate that depression is associated with worse glycemic control and health complications (69,70), as well as decreased quality of life (71), and is likely to be persistent (72). A recent meta-analysis confirms the association of depression with hyperglycemia and complications in both adult type 1 and type 2 diabetes (73). Evidence from prospective studies indicates that depression doubles the risk of the incidence of type 2 diabetes, independent of its association with other risk factors (74,75). In patients with preexisting diabetes, depression is an independent risk factor for coronary heart disease and seems to accelerate its presentation (76). Research has also shown that anxiety disorders are common in adults with diabetes and linked with poor glycemic control (68,77).

There is promising evidence that some of the adverse effects of depression and anxiety on diabetes are reversed by psychiatric treatment. Randomized controlled intervention trials have shown that treatment with either cognitive behavior therapy or antidepressant medication (nortriptyline or fluoxetine) can improve both mood and glycemic control (78,79). Psychopharmacologic interventions have been shown to reduce anxiety and improve glycemic control (80).

Studies indicate that eating disorders such as bulimia are common in adults with diabetes, especially young women with type 1 diabetes (81). Moreover, research has demonstrated that eating disorders are associated with poor glycemic control (82) and increased risk for retinopathy (22).

Research has also examined the effects of the social environment on diabetes management. For example, greater levels of social support, especially diabetes-related support from spouses and other family members, has been associated with better regimen adherence (83). High levels of environmental stress have been linked with lower regimen adherence (84) and poor glycemic control (84–86), but the effects of stress seem idiosyncratic and depend on a number of patient and situational factors, including the type of stressor and coping response and the prestress metabolic parameters.

Evidence also suggests that social support may buffer the negative effect of environmental stress on blood glucose (87).

Research has also examined the potential role of stress in the etiology of type 2 diabetes. For example, experimental studies with the *ob/ob* mouse have shown that environmental stress interacts with obesity to promote glucose intolerance (88). This hyperglycemic stress response is attenuated by anti-anxiety drugs and can be classically conditioned (89,90). Recent human studies support the idea that stress may increase the risk for type 2 diabetes (91).

Neurocognitive functioning. Neurocognitive deficits have been observed in adults with type 1 diabetes, particularly those with at least five episodes of severe hypoglycemia (92), and in patients with peripheral neuropathy (93). Among older adults with type 2 diabetes, cognitive deficits have been reported in association with poor glycemic control (94).

Quality of life. Diabetes-related quality of life can be reliably measured (95–97). Studies have shown that quality of life in adults with diabetes is positively affected by increased physical activity and adequate social support (98). Improved quality of life has also been demonstrated after intensification of insulin regimens, an effect attributed to patients' greater perceived flexibility in physical activities and diet (99). Quality of life is adversely affected by the presence of comorbid psychiatric disorders and health complications (71,100), as well as physical complaints and worries about the future (95). In addition, research has shown that quality of life is diminished when diabetes-specific health behaviors are associated with a sense of burden (101). When used as measures of treatment outcome, studies indicate that disease-specific quality-of-life measures are more sensitive to changes over time than are more general measures of health-related quality of life (102,103).

Psychosocial therapies. A number of controlled studies have evaluated the effects of psychosocial interventions for adults with diabetes. A recent meta-analytic review of diabetes self-management interventions indicated significant improvements in glycemic control, as well as reductions in diabetes-related hospitalizations and health care costs, particularly when interventions in-

corporated individually tailored strategies to change behavior (104).

For example, interventions that increase patients' sense of empowerment and self-management skills have resulted in improvements in self-efficacy, self-care behaviors, glycemic control, patient satisfaction, and quality of life (105–108). These benefits have also been found in studies with older minority patients with type 2 diabetes (109,110). Studies of blood glucose awareness training have shown that patients with type 1 diabetes can reduce the frequency of severe hypoglycemia episodes, diabetic ketoacidosis, and automobile accidents, as well as the fear of hypoglycemia (111).

BARRIERS TO RESEARCH PROGRESS

— A number of barriers exist that must be overcome for progress in research to continue. Most studies of personal and family factors in relation to adherence have relied on cross-sectional designs and self-report measures. There is a need for more longitudinal research that incorporates a variety of measurement approaches. In particular, studies of long-term psychosocial and behavioral functioning have not typically been conducted, especially with intensive insulin therapies. Intervention studies have, for the most part, been efficacy trials using small samples conducted at individual research sites. These relatively small sample sizes at individual research sites have limited the ability to study interventions that target specific patient groups (i.e., those that differ by age, gender, ethnicity, socioeconomic status, family structure, duration of diabetes, and presence of psychiatric disorders and health complications).

Improved glycemic control has been perceived as the single critical measure of treatment effectiveness. Although glycemic control is a major focus of intervention efforts, other types of outcomes, including regimen adherence, psychosocial functioning, and quality of life, are also worthwhile targets for intervention. In addition to focusing on outcomes for individual patients, other targets should include family relationships, work settings, and community-wide factors related to diabetes care.

Little consideration has been given thus far to psychosocial factors related to the use of new technologies in diabetes care, both as predictors and as conse-

quences of their clinical application. For example, screening for early markers of type 1 diabetes (islet cell antibodies) or genetic risks poses potentially significant psychosocial effects; however, relatively few studies have addressed these issues in clinical trials. Similarly, with the recent use of insulin pumps, new methods for inhaled delivery of insulin, and islet cell transplantation, psychosocial factors are not routinely considered in research designs.

Little attention has been paid to cost-effectiveness and efficiency in “real-world” clinical settings, and very few studies have systematically examined the translation of efficacious psychosocial intervention programs to clinical settings.

RECOMMENDED RESEARCH PRIORITIES

Children and adolescents

For children and adolescents, more longitudinal studies are needed to determine causal relationships among psychosocial factors, regimen adherence, and metabolic control. Intervention studies should include larger samples of patients from specific populations; this may require the use of multicenter studies. In particular, studies should focus on children and adolescents at developmentally critical transition times (newly diagnosed, very young preschool-aged children, preadolescent transition to adolescence, late adolescent transition to adulthood) during which preventive interventions can be provided. Research should also focus on high-risk patients (such as those with persistently poor regimen adherence and metabolic control), patients from low-income, single-parent families, and children with psychopathology (depression, eating disorders) and/or family dysfunction.

In this era of intensive therapies to achieve optimal glycemic control, more research is needed to determine the best ways to help children and their families succeed with intensive insulin therapies, both with multiple daily injections and with insulin pumps. It is also important to determine ways to prevent severe, recurrent hypoglycemia, particularly for patients on intensive insulin regimens. This is important because, on one hand, there is an association of hypoglycemia with neurocognitive deficits, and on the other hand, there is increasing use of intensive insulin regimens to reduce hyperglyce-

mia. Research is needed to determine the clinical significance of neurocognitive problems in children and adolescents, which may be related to both the history of glycemic control and age of onset of diabetes.

Research should particularly focus on the delivery of culturally sensitive interventions, especially with the expected growth of minority populations. This is especially relevant, considering that minority patients with type 1 diabetes are more likely to have poor metabolic control and considering the increased incidence of type 2 diabetes or impaired glucose tolerance among minority adolescents. Because few research findings are available concerning behavioral and psychosocial issues and therapies for the prevention and treatment of type 2 diabetes in youth, this area is considered a high priority. With all the different patient populations, there should be more use of theoretical models to guide intervention research.

Other research priorities are integrating behavioral and psychosocial services into routine pediatric diabetes care in clinical settings and addressing issues such as clinical significance, social acceptability, and cost-effectiveness. Such studies should include long-term follow-up to demonstrate maintenance of behavior change and positive health outcomes, as well as positive impacts on psychosocial functioning and quality of life. In addition to consideration of individual patients' functioning, it is also important to consider family relationships as outcome measures of psychosocial therapies.

More research focusing on dissemination and training is needed. In particular, such research should focus on the best strategies to educate health care providers about the importance of behavioral and psychosocial issues in treating children and their families and to train interventionists in implementation of efficacious treatment programs for selected patient groups.

Adults

More studies should focus on the identification of specific psychosocial factors that influence regimen adherence and glycemic control in adults with type 1 and type 2 diabetes. Such studies should incorporate large patient samples and use longitudinal designs. For example, longitudinal studies can determine mecha-

nisms to account for how psychosocial factors and health behaviors affect health over time. Results from such studies can inform the development of more effective interventions for specific patient populations.

Sample sizes should be sufficient to have the power to detect effects among various patient subgroups. Specific patient populations include ethnic minorities, individuals with low socioeconomic status, the elderly, individuals who live alone or without social and family support, and individuals with psychiatric disorders and/or diabetes-related health complications. Considering the frequency of psychiatric disorders, research must establish methods of effective intervention with patients who have depression, anxiety, and eating disorders. More research is needed to assess how to improve self-management skills, empowerment, coping skills, and stress management to promote long-term health and quality of life for these special patient populations. Theory-based intervention studies are needed to determine how to individualize (i.e., tailor) psychosocial therapies to improve regimen adherence, glycemic control, and quality of life in the different patient populations.

Another research priority is conducting multicenter clinical trials to document the efficacy of initial findings drawn from smaller, single-site intervention studies. Research should be conducted that evaluates the integration of psychosocial intervention into disease management program, e.g., by targeting high-risk patients. Cost-effectiveness trials in “real-world,” managed care settings are needed to assist in the translation of research findings to clinical practice. The effectiveness of behavioral and psychosocial interventions must be demonstrated in clinical settings and shown to be cost-effective for more widespread implementation of these therapies to occur.

CONCLUSIONS— A substantial amount of behavioral science research has demonstrated that psychosocial factors play an integral role in the management of diabetes in both children and adults. Research has demonstrated the efficacy of a number of psychosocial therapies that can improve regimen adherence, glycemic control, psychosocial functioning, and quality of life. More research in this area is needed to develop psychosocial in-

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