LITERATURE SEARCH AND APPLICATION: INTERVENTIONS FOR CHILDREN WITH INSULIN-DEPENDENT DIABETES MELLITUS

By Bridget M. Colacchio

This article presents the results of a literature search designed to demonstrate the guidelines for conducting an evidence-based investigation as outlined by Leonard Gibbs (2003) and to identify interventions used in the psychosocial treatment of children with insulin-dependent diabetes mellitus (IDDM). The article will also propose strategies to apply and implement those interventions in a treatment plan for patients and families at Children's Memorial Hospital in Chicago. Application and implementation strategies focus on a community-based, family support intervention adapted to fit the needs of the hospital's patient and family population, as well as the parameters of the hospital setting.

Diabetes has come to be associated with obesity, poor eating habits, and lack of exercise. Though bearing similar names, the two types of diabetes—Type I diabetes, or insulin dependent diabetes mellitus (IDDM), and Type II diabetes, or adult-onset diabetes—are quite distinct. The diagnoses, symptom sets, treatments, and prognoses are different. So, too, are the sociocultural perceptions of the two diseases. One such distinction is that IDDM develops during childhood. Like many childhood diseases, there is nothing that a child or a parent can do to prevent or predict the development of IDDM (Grey, Genel, and Tamborlane, 1980; Grey et al., 1995). Thus, the onset of diabetes in children is a shocking and disturbing event for families.

The condition that precipitates discovery of IDDM can be a swift, severe, and frightening sickness in a child. This initial event can be an extremely devastating experience for a family. Research documents the profound physical, emotional, and familial stress that follows the ultimate diagnosis (Auslander et al., 1990; Grey et al., 1995).

At Children's Memorial Hospital in Chicago (hereafter, Children's), much attention is devoted to the newly diagnosed IDDM patient and his or her family.[1] The diabetes team consists of doctors, residents, nurses, certified diabetes educators, social workers, and psychologists. Each member of the team descends upon the often-startled family during their first 2 days at the hospital, offering information and support. Immediately, families learn that their children must control their illness by following a structured regime. This regime includes guidelines for diet, exercise, and blood-sugar level monitoring, as well as for administering insulin and other medications. After the child is stabilized, parents are expected to learn to monitor blood sugar levels and administer insulin shots within 1 day. Families quickly understand that the management of the child's diabetes starts immediately and the illness will affect every part of their lives.

PROBLEM IDENTIFICATION AND CASE EXAMPLE

After the initial discharge from the hospital, the child with IDDM must return to the endocrinology clinic every 3 months for a diabetes checkup. It is during these checkups, or a visit to the emergency room, that the diabetes team may discover that a child's illness is being poorly managed. The author witnessed this phenomenon-particularly in girls between the ages of 9 and 13—on several occasions during her time at Children's. A simple blood test (A1C) is conducted in the clinic and reveals the 3-month average blood sugar level for the child. When that average is too high, the team becomes concerned about how the child and family are dealing with the diabetes on a daily basis. One child, Krista, and her family exemplify a pattern of emotion and behavior that the author found to be common among preadolescent girls and their families as they struggle with the management of the child's diabetes.[2]

Krista is an 11-year-old Latina female who was diagnosed with IDDM in April 2002. Her A1C level was high at her regular 3-month appointment in the fall of 2004; it was more than twice the recommended level. She and her family were referred to a social worker because Krista's mother mentioned that she and Krista were not getting along well. The mother explained that they were arguing about Krista's diet and, more specifically, said that the girl was yelling at her mother when she reminded Krista not to eat too much or not to eat certain foods. Krista agreed and said that she often became angry with her mother. After some discussion, Krista also admitted that she hated being different from her friends and that she didn't like being on a special diet. She said she got tired of having diabetes. In the same conversation, Krista's mother expressed her own frustrations with Krista's illness, particularly how arguments around Krista's diabetes care were creating tension in their home. Krista reported that when she gets upset at her mother, she goes to her room by herself and listens to music. She also told the author that she sometimes buries her head in a pillow and cries. The author learned from Krista's mother that her performance in school was also suffering. Krista admitted that she sometimes did not check her blood sugar at school as required. Also, the author inferred from Krista and her mother's stories about the girl's daily routine that Krista was not supervised when checking her sugar at home. In a later session when Krista was not present, her mother volunteered that her relationship with her husband was being strained because she felt he was not an equal partner in attending to Krista's medical needs.

The problems identified through interviews with Krista and her family include unmanaged family stress and negative emotions related to Krista's illness. It was the author's clinical impression that Krista and her parents had not integrated diabetes into their understandings of their lives; they continued to combat the illness and that prevented them from making peace with it. Krista's lapses in medical adherence (i.e., not following her diet, checking her blood sugar regularly, or taking her insulin shots as directed) were also a great concern.

RESEARCH QUESTION

This family continued to struggle, seeking help and guidance in order to effectively address the stress and negative emotions they associated with diabetes. These issues affect Krista and the whole family. In searching for specific resources and counseling interventions to help the family, the author pursued information using a Client-Oriented, Practical, Evidence-Search Question (COPES question; Gibbs, 2003). According to Leonard Gibbs, the COPES question is the first step in conducting an effective literature search using online, academic databases. The question is created with specifications of the client type, clinical problem, and intended clinical outcomes for a particular client. Based on Krista's situation, the author formulated the following COPES question: For 8- to 12-year-old girls newly diagnosed with Type I diabetes, what is the most effective intervention to promote better postdiagnosis self-esteem and adjustment to illness?

LITERATURE REVIEW

Search results indicate that Type I diabetes is a well-studied chronic disease.

Many facets of the illness and the characteristics of its sufferers have been researched and described at length. The author identified three foci of particular interest: (1) descriptions of the population (i.e., children and adolescents with IDDM and other chronic illnesses), (2) problems in this population that are targeted by various interventions, and (3) different types of interventions studied for use with this population.

Descriptive Studies of the IDDM Population

A body of research describes features of chronic childhood illnesses that might also be associated with children with IDDM. Theora Evans (2004) suggests that children with chronic physical conditions (including diabetes) are at risk of unhealthy psychosocial outcomes. Social workers and other clinicians would do well, according to Evans, to use developmental theory and strengths-based assessments of children with chronic illnesses as tools for successful planning of interventions. Two studies (Erstling, 1988; Ell and Reardon, 1990) comment on how emerging medical and other technologies affect the population of chronically ill children. Technology often extends the lives of ill children, and it also offers new possibilities for intervention strategies. Susan Erstling (1988) points out that when families are dealing with the stresses associated with a chronic childhood illness, they often neglect other developmental tasks important to the child's growth. These issues illustrate how chronic illnesses of different kinds can generate similar concerns for families.

Much research has also been conducted specifically within the IDDM population. Exploratory studies provide information regarding common characteristics of the illness and of those who live with it. Wendy Auslander and associates (1990) investigate how a Type I diabetic child's health status and disease management might be associated with certain psychosocial, demographic, and familial factors. They find that control of the diabetes is associated with race, socioeconomic status, family cohesion, and number of parents living in the child's home. More specifically, their analysis indicates that black children from single-parent homes are at higher risk for poor diabetes management than other children. In 1993, Auslander worked with a new team of researchers to find that high levels of family stress and few family resources are associated with poor blood sugar regulation in children with IDDM (Auslander et al., 1993). Family functioning is also the focus of a study by Margaret Grey, Myron Genel, and William Tamborlane (1980). These authors find that parental self-esteem correlates closely with a child's adjustment to his or her diabetes. Another study conducted by Grey and associates (1995) finds that children with IDDM differ from their peers without diabetes in terms of levels of depression and adjustment. Using scales to measure depression, anxiety, adjustment, and self-perception, the authors discover that children with IDDM experience twice as many depression and adjustment problems as their peers (Grey et al., 1995). These and other descriptive studies of children with IDDM illustrate some of the characteristics and troubles of the childhood diabetes population. Studies of this sort can be useful in guiding the creation of interventions that support families coping with diabetes.

Target Problems

The literature search also yielded information about the different issues faced by children with diabetes (or other chronic illnesses), as well as by their families. Comparing children with epilepsy to children with diabetes, Hoare and Mann (1994) find that children with epilepsy have consistently lower self-esteem and poorer behavioral adjustment to their illness. In general, the author's search findings indicate that self-esteem is a frequently discussed target problem examined by a variety of intervention studies (e.g., Herskowitz, 1990; Daley, 1992). Researchers have also shown interest in children's adjustment and response to their illness. Diana Brown, Kathleen Krieg, and Frances Belluck (1995), for example, study the effectiveness of an intervention strategy on the adaptive and functional responses of children with cystic fibrosis.

In a longitudinal study, Maria Kovacs and colleagues (1990) investigate the relationship between the health status of children with IDDM and their later adjustment to the illness. They find that adjustment (measured by levels of depression, anxiety, and self-esteem) is not associated with a child's number of hospitalizations or the child's blood sugar regulation. Other studies explore intervention effectiveness in terms of its impact on physical health (Campbell and Patterson, 1995), family functioning (Grey et al., 1980; Auslander et al., 1990; Wysocki et al., 1997), and depression (Chernoff et al., 2002). The search results did not identify adherence to medical protocol for diabetes management as a possible target problem. Future studies might examine how other issues, like depression and family conflict, affect a child's medical adherence.

Types of Interventions

To address some of the problems identified above, researchers and clinicians utilize a wide variety of intervention strategies. In an effort to counter low self-esteem in teens with IDDM, Beverly Daley (1992) implements an intervention in which teens are matched by demographic criteria with an insulin-dependent adult. These adults act as sponsors to the teens, meeting with them for informal visits in order to provide social support, offer validation, and, ultimately, improve medical adherence. Teens in Daley's (1992) experimental group were less likely to agree with statements demonstrating low self-esteem and poor illness adjustment than teens in the control group. Raymonde Herskowitz (1990) discusses another creative intervention strategy: an Outward Bound wilderness experience for people (ages 14-42) with Type I diabetes. During this experience, participants took part in six outdoor challenge courses. Outcome measures suggest modest improvements in diabetes adjustment and self-esteem (Herskowitz, 1990).

In one extremely informative article, Wendy Plante, Debra Lobato, and Romy Engel (2001) review 125 studies describing group interventions for children with chronic medical conditions. They categorize these interventions along one or more of the following program types: emotional support, psychoeducation, adaptation or skill development, symptom reduction, and summer camp (Plante et al., 2001). Plante and associates judge adaptation and skill development groups to be the most "*well-established* [original emphasis] for improving physical symptoms and psychosocial functioning among children and adolescents with diabetes" (2001, p. 439), as compared with the other types of interventions.

Other studies examine family behavioral therapy (Wysocki et al., 1997), medical family therapy (Campbell and Patterson, 1995), and strengths-based, psychosocial family therapy (Erstling, 1988). Findings in each of these studies support the effectiveness of family therapy in the treatment of a variety of individual and familial challenges associated with chronic illness.

Robin Chernoff and associates (2002) conducted a study that combines some of the successful ideas presented above: family-focused, group interventions targeting self-esteem and adjustment via an adaptation and skill-development approach. In that study, families and the community were involved in a support program for chronically ill children. The randomized, controlled trial demonstrates statistical significance in the positive adjustment and mental health outcomes in the experimental subjects. The most significant outcome of this study, improved adjustment, was more pronounced among higher risk children (i.e., higher risk because they had poor self-esteem at the beginning of the program; Chernoff et al., 2002).

INTERVENTION PLAN

In light of the aforementioned literature, the author determined that the study by Chernoff and associates offers the most promising intervention strategy to achieve the desired outcomes (postdiagnosis self-esteem and adjustment to illness in children with diabetes) delineated in the COPES question. If the determination is correct, this intervention may yield positive results for Krista and her mother, as well as for other such families.

Intervention Description

Chernoff and colleagues (2002) created and implemented the Family-to-Family Network. Families participating in the intervention program are enrolled for a period of 15 months and, ideally, continue for the program's duration. The intervention is comprised of two concurrent components: one for the children and one for their mothers. The children's component, Kids Involved in Discovery and Sharing (KIDS), involves group work and home visiting. These two elements of KIDS are conducted by child life specialists (CLSs) from the Johns Hopkins hospital in Baltimore. These CLSs lead the children in group activities that reflect the program's objectives. One objective, for instance, involves improving the children's perception of their physical appearance. The group activities (e.g., role plays, reading stories, making a scrapbook, tracing the child's body) focus on helping the children master self-praising messages, such as "what's right with my body," "what I'm good at," and, "liking how I look." In addition to activities in a structured group setting, CLSs also make seven home visits to each family. They make monthly phone calls to the families, distribute newsletters and other correspondence, host periodic lunches for two to four families, and facilitate larger social outings for all of the children and families in the program.

The second component of the Family-to-Family Network focuses on the mothers. This part of the program is facilitated by expert mothers. These women have experience in dealing with a child who has one of the four illnesses. The program refers to them as Network Mothers (NMs). Like the CLSs, the NMs also visit the families (either in the home or out in the community) and initiate contact via phone calls. Both CLSs and NMs work collaboratively in the planning of the family events described above. They meet regularly with one another, and with other team members (doctors and social workers). These meetings ensure that the program is implemented as planned and facilitate a forum for mutual guidance and support among the team.

Two independent sources describe the components of the intervention in additional detail. Munn and colleagues (2000) outline the theoretical framework and applied activities used in the children's component. The second source, an article by Henry Ireys and associates (2001), discusses the details of the maternal component and presents the maternal outcomes of the intervention study. These sources provide the information necessary to replicate the intervention in another setting, such as Children's Memorial Hospital.

Measurement

The Family-to-Family Network uses four indicators of child mental health to assess each participant at the beginning of the intervention. These indicators are also used to assess the effects of the intervention upon its completion. Children's self-esteem is measured by the Self-Perception Profile for Children (Harter, 1985), which consists of 4 individually scored subscales: physical appearance, social acceptance, athleticism, and global self-worth. A self-report tool, the Children's Depression Inventory (Kovacs, 1992), is used to measure depressive symptoms. The Revised Children's Manifest Anxiety Scale (Reynolds and Richmond, 1978), measuring general anxiety, is also a self-report measure. The final measure is the Personal Adjustment and Roles Skill Scale III (PARS III; Stein and Jessop, 1990), which is completed by the children's mothers. The scale has a total adjustment score and 6 subscales: hostility, anxiety and depression, dependency, withdrawal, productivity, and peer relations. The subscales are scored separately. Chernoff and associates (2002) review these measures for reliability, validity, and consistency. Other well-tested measures of child mental health could be used in place of these four tests, but with caution. In order to maintain the dependability of the intervention as a whole, any other measures must provide equal or greater reliability, validity, and consistency.

Application and Implementation

Several factors demonstrate that the Family-to-Family Network intervention is applicable to the diabetes population at Children's Memorial Hospital. Chernoff and colleagues (2002) identify risk for mental health problems and poor adjustment to illness-related change as concerns in children with chronic illnesses. Sandy Rubovits, a licensed clinical social worker, is the author's clinical social work supervisor at Children's and has worked with the endocrinology team at Children's for 10 years. She commented to the author on October 22, 2004 (Sandy Rubovits, personal communication, October 22, 2004) that the medical team's concerns parallel those mentioned above. These concerns include questions as to how to improve the experience of patients and families after this difficult diagnosis. Within the normal protocol of medical, developmental, and psychosocial services provided by the hospital, not all of the needs of families are being met. The Family-to-Family Network attempts to address these unmet needs.

Demographics is another factor that promotes the intervention's applicability to Children's. Like the city of Baltimore, MD, where the intervention was first delivered, Chicago is a diverse, urban setting. The intervention's sample was diverse in terms of race and family composition, as well as in respect to socioeconomic status and educational attainment of mothers (Chernoff et al., 2002). Most participants were between the ages of 7 and 11, and were in good to very good health at the time of the study (Chernoff et al., 2002). These demographic characteristics parallel some of those in the patient population of the diabetes program at Children's. The largest group of intervention participants in the study (Chernoff et al., 2002) is associated with diabetes (41 percent). Because the study finds significant benefits with all participants, and most participants were associated with diabetes, the author infers that the intervention would be applicable to the diabetes population at Children's. Race is one demographic inconsistency between the population of the study and that at Children's. Rubovits reported that the racial breakdown of the diabetes program parallels that of the hospital population as a whole (Sandy Rubovits, personal communication, October 22, 2004). Children's serves a greater percentage of Latino families (about one-third of all families served at Children's are Latino; Children's Memorial Hospital, 2003) than the corresponding percentage of Latinos in the study.

The Family-to-Family Network intervention is also compatible with Children's commitment to interdisciplinary leadership. Children's employs CLSs who work on each of the hospital's services and collaborate with all other hospital professionals to deliver care to families. It is certainly conceivable that an interdisciplinary team could work together in the implementation of the Family-to-Family Network. Moreover, Children's endocrinology team of doctors, nurses, social workers, diabetes educators, psychologists, child life specialists, and auxiliary staff are supportive of interdisciplinary initiatives to enhance the overall health and well-being of patients and families (Sandy Rubovits, personal communication, October 22, 2004). Also, expert parents and families are used both formally and informally as important resources at Children's. The hospital often turns to seasoned parents and families to share their wisdom of experience with others in similar health related situations. For these reasons, the author surmises that the Family-to-Family Network could be successfully replicated at Children's.

Conditions for Implementation

While the case is strong for fidelity to the original intervention program, challenges could impede its implementation at Children's. The analysis of Chernoff and associates (2002) reveals that there is no significant association between the dose of intervention (i.e., the length and frequency of written, phone, and face-to-face contact) and participant outcomes. Chernoff and associates (2002) hypothesize that because most participants received what they call a low dose of intervention, the full potential of the program may not be evident from their results. In response to that observation, the author infers that the dosing standards outlined in the intervention should be similarly followed at Children's.

Chernoff and associates (2002) do not measure patient adherence to medical protocol. This is another serious concern for the diabetes team at Children's because psychosocial issues like self-esteem and adjustment may affect adherence (Sandy Rubovits, personal communication, October 22, 2004). In addition, the intervention offers few opportunities for the involvement of fathers, siblings, and other close family members affected by the illness of their loved one. The author advises revising the methodology of the intervention in order to include these important family members in the program.

Chernoff and associates (2002) also fail to report on analysis of the relationship, if any, between intervention effects and the amount of time from the date of a participant's diagnoses to the start of the program. The researchers exclude children whose diagnoses occurred less than 6 months before the beginning of the program. No data was provided concerned the average months or years elapsed between diagnosis and intervention. Other studies (Kovacs et al., 1990; Grey el al., 1995) indicate that the first 2 years after diagnosis are fraught with difficulty and, thus, are an important time for intervention. Rubovits affirms that families who ultimately struggle with a new IDDM diagnosis will often do so within the first 6 months (Sandy Rubovits, personal communication, October 22, 2004). In order to prevent future postdiagnosis problems, the author recommends that this 15-month intervention be made available to patients within the first 6 months after IDDM diagnosis. The intervention should also be extended into the second year after diagnosis.

Some of the barriers to the implementation of the Family-to-Family Network include limitations of time and money. The intervention would extend the hours of the intervention team and such extensions would require compensation. Hospital employees who already work at least a full 40-hour week could not be expected to work overtime for the implementation of this program. It may be necessary to hire new employees to cover the extra time for running the groups and making home visits. It may also be difficult to ensure that patients and families remain in the program for the entire 15-month duration. Chernoff and associates (2002) do not consider the possible effects of a rolling admission, but that kind of flexibility might be necessary in order to reach more families at Children's.

CONCLUSION

The relevance of the Family-to-Family Network in the treatment of poor self-esteem and in the adjustment of children with chronic illnesses is supported by the literature. More specifically, the intervention's objectives and methods correspond well with those of the diabetes team at Children's Memorial Hospital. Challenges may arise in implementing this intervention outside of its original context, but the program's potential is promising. If it had been implemented early for Krista's family, it might have been able to mitigate some of the struggles they have experienced since her diagnosis. Perhaps, through the Family-to-Family Network, families like Krista's could get involved in the promotion of health and well-being for other children and families. ■

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NOTES

[1] Much of the contents of this article, particularly the materials pertaining to specific procedures, practices, and events at Children's Memorial Hospital, are derived from the author's participation in a master's-level social work field placement at the institution (from Sept. 2004 to May 2005). Thus, the personal experiences and conclusions described herein should not be considered final, objective, or independently verifiable evidence.

[2] In order to preserve the confidentiality of this study's subjects, the names of all subjects have been changed and the dates of reported events are not disclosed.

ABOUT THE AUTHOR

BRIDGET M. COLACCHIO is a second-year master's candidate at the University of Chicago's School of Social Service Administration. Her professional experience includes working in high school, community mental health, and hospital settings. The impetus for this article came from observing the struggles faced by families of children with Type I diabetes. Ms. Colacchio plans to continue doing therapeutic treatment to children and families in the Hispanic population upon graduation.