Review Article

Working with families who have school-age children with type 1 diabetes

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Abstract

Families of school-age children who suffer from type 1 diabetes are always in need of a special care and support. Reaching of diabetic control in those children without having hypoglycemia or limitating their daily activities have a burly emotional impact and can give rise to many of the mental illnesses on their parents. Children with type 1 diabetes are always in need of a high degree of attention and organization inside and outside the house, especially at school. To apply the concept of family system theory on school-age children with type 1 diabetes; explore the biopsychosocial impact of having school-age children with type 1 diabetes on the family; and implement a family-centered group education program for families of school-age children with type 1 diabetes, reviewing of the topics from different directions that related to concerns of the parents and teachers and its psychosocial impact was carried out. The role of the school nurses in making a link between the children with type I diabetes, parents, teachers, and hospital was also emphasized. Searching evidence for relating researches and their important conclusions was also done. The prevalence of parental psychological distress across all the studies ranged from 10% to 74%, with an average of 33.5% of parents reporting distress at diagnosis and 19% of parents reporting distress 1 to 4 years after diagnosis. Parental psychological distress also had negative effects on diabetes management. Furthermore, studies indicated that there are relationships between the child's chronic and marital communication, between the child's disease and parental attitudes, and, thus, between the disease and the functioning of the whole family system. Many studies have proved that the development of special strategies for the families of school-age children with type 1 diabetes such as communicate with other families, give joint appointments, family-centered interventions programs, and screening for mental illness is very important to make a healthy and productive family.

KEY WORDS: Type 1 diabetes, family counseling, communications, family theory, family crisis

Introduction

Diabetes is a chronic disease that affects multi organs from the head to the toes and is "one of the most common chronic health conditions in children and adolescents".[1] Type 1 diabetes (T1DM) is a metabolic disorder characterized by high blood sugar because of autoimmune destruction of B cell of Islet of Langerhans in the pancreas, which leads to severe insulin deficiency.[1]

Families of school-age children who suffer from chronic diseases in general andT1DM, in particular, are always in need of a special care and support. Reaching of diabetic control in those children without having hypoglycemia or limitating their daily activities have a burly emotional impact on the parents of school-age children with T1DM. It can give rise to many of the mental illnesses on parents such as depression, anxiety, and post-traumatic stress disorder (PTSD).[2]

One of the hard experiences is the presence of a child suffering with diabetes in the family, because families that have a child with diabetes feel that they cannot help their children and keep them away from the consequences of

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this disease. Moreover, they need a high degree of attention and organization inside the house in terms of the quality of eating and drinking and outside the house, especially at school where they need a lot of care in terms of the organization of meals, insulin injections, blood glucose testing, and physical activity.[2]

The illness has also been recognized as having a major impact on the life of the child and family, because it requires a higher degree of behavioral regulation than is normal for children of the similar age.[2]

Even with the development of modern and advanced treatments for diabetes such as insulin pumps, the risk of complications in diabetes still exists because these treatments reduce the rates of complication but do not eliminate them.

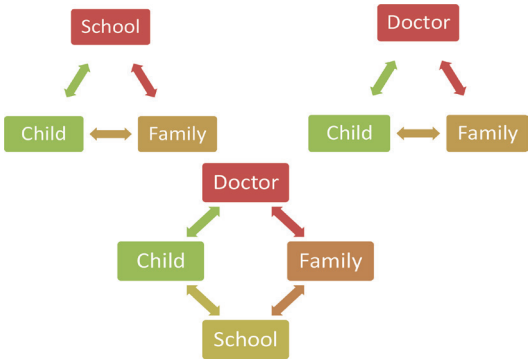

Figure 1: Therapeutic triangle.

Objective

1. To apply the concept of family system theory on school-age children withT1DM.
2. To explore the biopsychosocial impact of having school-age children with T1DM in the family.
3. To implement a family-centered group education program for families of school-age children withT1DM.

Case Study

Laura Plunkett faced the major challenges was the reason for changing her life and her family's life when her son Danny was diagnosed with T1DM.

She told her story in 41st NASN (National Association of School Nurses) Annual Conference in Boston, MA, June 2009, and said "We rushed to Children's Hospital Boston and then spent three days and two nights learning how to give shots, measure insulin, count carbohydrates, plan four snacks and three meals per day, and test his blood sugar every two hours. Insulin doses had to take into account food, exercise, growth hormones, stress, and the location of where we gave him his shot. If we gave him too little insulin, he felt sick, tired, and shaky. If we gave him too much insulin, he could fall into a coma or have a seizure. In those first months after diagnosis, my husband and I barely slept. After we got home from the hospital, I drove my two children to school and sat in the cafeteria every day for six weeks because there was no school nurse. I tested his blood sugar at 8 a.m., 10 a.m., 12 p.m., and 2 p.m., and in between, I called in to the nurse at Children's Hospital to find out what to do about whatever blood sugar number he had. After six weeks, Danny's teacher learned enough to supervise him and I started going home, unless there was a substitute teacher. His 10-year-old sister was listed as the most prepared person to call into the room if there was an emergency. Several years later, when Danny switched schools, we had our first school nurse experience. It was amazing and changed our family's life. The school nurse understood that Danny could not learn, take tests, or succeed on the state standardized tests if his blood sugars were too low or too high. Together we developed one page Emergency Care Plans with Danny's photo and our phone numbers. I realized that I was about to experience 8 a.m. to 2:30 p.m. without being the only one who really knew how to help him."[3]

Therapeutic Triangle

Cooperation between the family, doctor, and school in dealing with school-age children with T1DM is an important element in maintaining the cohesion of the family and face psychological, social, physical problems and even prevent them.

I will discuss these elements and explain the existing concerns and effects and how that cooperation among them help in reaching a family-centered group education.

Parents

Parents Concerns

At diagnosis: T1DM occurs suddenly, and children often in poor condition, and perhaps in the hospital in the intensive care unit, pose a significant emotional impact on parents where they think they will lose their children.

During treatment: One of the most important things that parents worry is that insulin is the only treatment for T1DM, and parents face the responsibility to give their children injections that may be painful for them. Moreover, frequent blood sugar testing several times a day and recording the results carry them other responsibilities.

Fear of complications: Parents may fear of diabetes complications on their children, whether short-term complications, such as hypoglycemia, hyperglycemia, ketoacidosis, or coma, and long-term complications that may affect the child's eye, kidney, heart, or development.

School concerns: School staffs, especially teachers, do not have adequate training and experience to take care and follow-up of children who suffer from T1DM. Moreover, they cannot recognize the hypoglycemic attacks and deal with it and take care of their diet and what physical activities are appropriate for them.

Psychological effect on parents: Many parents of school-age children with T1DMare exposed to various psychological problems such as anxiety, depression, and sleep problems in addition to the financial pressures.

Studies have shown that "Twenty percent of fathers will meet the full diagnostic criteria for Post Traumatic Stress Disorder after their child is diagnosed with diabetes and more than half will show many of the symptoms."[3]

School

The most important reason why school is an essential element in dealing with children with T1DM is that they "spend during the school years more than half of their waking time in school setting."[1]

One of the most important duties of the school is to help children with T1DM to maintain an excellent level of academic achievement and integrate them with the other students. Furthermore, make them actively participate in school activities, while providing a safe environment for them to maintain a normal range of blood sugar in order to be keeping them healthy.

Teachers Concerns

There are also concerns of teachers about children with T1DM with regard to the possibility of having hypoglycemic attack and entry into a coma, where teachers do not have the ability to find out why and deal with it.

School Nurse

The school nurse is a very important link between the children with T1DM, parents, teachers, and hospitals who helps to regulate the treatment of these children properly. Moreover, "for parents their relationship with the school nurse can greatly relieve their anxiety and help to improve their child's blood glucose control."[1]

The Evidence

Differences in marital communication and parental attitudes between parents of healthy children and parents of children with type 1 diabetes [4]

"Fathers of diabetics assess themselves to be less supportive towards their wives than the fathers from the control group. However, they evaluate their wives' to be supportiveness and involvement similarly to the fathers of healthy children".

"Mothers from the study group evaluate themselves in terms of marital communication on an equal level as compared to mothers from the control group. However, they perceive their husbands to be less supportive and less involved in the marital relationship than the females from the control group do."

Interpretation

"This indicates that there may be a relationship between the child's chronic and marital communication, as well as between the child's disease and parental attitudes, and thus between the disease and the functioning of the whole family system."

***Cognitive and non-cognitive factors associated with post-traumatic stress symptoms in mothers of children with type 1 diabetes*[5]**

Results

"All cognitive variables were positively associated with PTSD symptoms. In contrast, of the non-cognitive variables, only social support was significantly (negatively) associated with PTSD symptoms."

Parenting children living with type 1 diabetes: A qualitative study

Implications

"Findings indicate that there is a need for greater diabetes education in schools. Diabetes educators can play a more proactive role in leading school based discussions with children, parents, and school staff."

***Psychological experience of parents of children with type 1 diabetes a systematic mixed studies review*[7]**

Results

"The prevalence of parental psychological distress across all studies ranged from 10% to 74%, with an average of 33.5% of parents reporting distress at diagnosis and 19% of parents reporting distress 1 to 4 years after diagnosis. Parental psychological distress also had negative effects on diabetes management."

***Review of family centered interventions to enhance the health outcomes of children with type 1 diabetes*[8]**

Results

"Findings indicated that family centered interventions significantly improved A1Cs, enhanced family dynamics, and decreased family conflict."

***Relating parent and family functioning to the psychological adjustment of children with chronic health conditions: What have we learned? What do we need to know?*[9].**

Interpretation

"More adaptive family relationships and parental psychological adjustment were associated with positive psychological adjustment while less adaptive family relationships (e.g., greater conflict and maternal psychological distress) consistently predicted problematic adjustment."

***An intervention to decrease uncertainty and distress among parents of children newly diagnosed with diabetes: A pilot study*[10].**

"The intervention was designed to decrease parental uncertainty and distress, as well as child behavioral problems by teaching parents skills to manage uncertainty."

***Everyday experience of families three years after diagnosis of type 1 diabetes in children: A research paper*[2]**

"The findings suggest that all family members had integrated the diabetes management regimen in different ways; however, in their daily life, they were affected to different degrees by the illness."

***Can addressing family relationships improve outcomes in chronic disease? the family approach to diabetes management: Theory into practice toward the development of a new paradigm*[11].**

"We suggest that a broader social and ecologic perspective to the management of chronic disease has several advantages compared with other approaches."

Approach Toward Families Who Have School-Age Children with Type 1 Diabetes

Communicate with other families that have children with T1DM, whether through a social worker in the hospital or the school nurse at school for communication and exchange of experiences, something important where children feel a sense of belonging.

Give joint appointments for children with T1DM and their families at the hospital to discuss the important issues that relate to these children and their families and how to deal with the existing concerns and what the existing collaboration between home, school, hospital, and those children is.

The evidence shows that "including the family in diabetes care has been shown to play an important role in the successful management of diabetes in children and better metabolic outcomes have been reported among those children.""[8]

Family-Centered Interventions for Children with T1DM

We have many types of family-centered interventions for children with T1DM:

1. Behavioral Family System Therapy (BFST)
2. Behavioral Family System Therapy for Diabetes (BFST-D)
3. Family Therapy (FT)
4. Multifamily group
5. Multisystemic therapy (MST)
6. Self-management training (SMT)
7. Teamwork (TW)

The description of each of these types was previously published with more details about study design and outcome of randomized clinical trials (RCTs) of family-centered interventions for children with T1DM in an article of McBroom and Enriquez.[8]

Screening for Mental Illness in Parents of Children with T1DM

Screening for mental illness in parents of children with T1DM is important to detect any abnormalities early and make the appropriate referrals either to the family physician or psychiatrist. A study revealed that screening takes less than 5 min in 95% of the population.[7]

Conclusion

Families of school-age children with T1DMare always in need of an extraordinary care and support, including collaboration between the family, doctor, and school to ensure the cohesion of the family, face psychological, social, and physical problems, and prevent them.

The role of the school nurse is very important in taking care of the school-age children with T1DM and in reassuring their parents and raising awareness among their teachers.

Recommendation

Many studies have proved that the development of special strategies for families of school-age children with T1DM such as communicate with other families, give joint appointments, family-centered interventions programs, and screening for mental illness is very important to make a healthy and productive family.

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