



# Chronic Illness and its Impact on School Children and Their Families

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# Organization of Presentation

- Esther Stavrou - Overview of the role of the school psychologist in working with children with chronic illness
- Elana Dumont - Type 1 Diabetes
- Jessica Hartman - Asthma
- Jennifer Guegen Weber - working with children with a parent diagnosed with cancer

# Chronic Illness

- **Definition:**
  - *A medical condition, lasting for more than 3 months, which requires medical attention and interferes with a person's daily living (Bilfield et al, 2005)*
- **Prevalence:**
  - Approximately 12% of US school children are affected by chronic illness ([www.cdc.gov](http://www.cdc.gov))

# Chronic Health Conditions in Children

- **Most Common**
  - Asthma
  - Heart Conditions
  - Seizure disorders
  - Cancer
  - Juvenile arthritis
  - Cystic fibrosis
  - Bleeding disorders
  - Diabetes
  - Gastrointestinal disorders

# Role of the School Psychologist

- Schools can play an important role in fostering resilience and minimizing risk in children with chronic medical conditions or coping with an ill family member

# Role of School Psychologist (contd.)

- 1995-Power, DuPaul, Shapiro, & Parrish described subspecialty in pediatric school psychology
- Need for training of school psychologists has become even more important
  - emphasis on expanding school-based services to ensure healthcare to as many children as possible
  - Advances in medical technology allow more students with illnesses to attend school
  - rates of chronic illness have increased.
  - school psychologists not trained in this specialty area may feel unprepared.

# Need for training

- School psychologists report that they are frequently involved with chronically ill students (e.g. coordinating OHI and 504 plans, transition plans and educating school personnel about various illnesses)
- However, 72% of respondents indicated that they felt they needed greater training

Barraclough, C. & Macheck, G.R. (2010)

# Need for training

- Medication Side effects (70% reported need)
- Symptomology of chronic illnesses
- Ways to better support families
- Features of the illness that commonly appear in school setting

Barraclough, C. & Macheck, G.R. (2010)

# School Psychologists can help by:

- Assisting the child in integrating health care behaviors in the school setting
- Using behavior management techniques to help increase compliance with treatment regimens
- Acting as a liaison between medical and school personnel and family
- Encouraging clear communication among physicians, parents, teachers and administrators
- Assisting children in learning social skills for interacting more effectively with peers
- Providing support groups for children with chronic illness

# Formal Services

- **IDEIA**
  - Child may qualify for services if condition “adversely affects a child’s educational performance”
- **Section 504 of Rehabilitation Act**
  - For those who have special needs but don’t meet the criteria for receiving services under IDEIA

# Facilitating Re-entry into school

Madan-Swain, Katz & LaGory, 2004

- Prepare child
- Prepare teacher
- Prepare class/peers

Shaw & McCabe, 2008

- Traditional transition programs may need to be modified due to changes in medical service delivery

# Re-entry

- Prepare child:
  - Give adequate information about the disease
  - Prepare for what questions might be asked by peers and teachers and what responses can be given in return
  - Coping strategies to deal with teasing

# Re-entry

- Prepare teacher

- Nature of child's illness, prognosis and how it's being treated
- Specific treatment side effects
- Child's physical capabilities or limitations
- Discuss what child knows about his/her disease
- What do parents want the class and other school staff to know
- What would child like peers to know
- Schedule of any upcoming medical appointments

# Re-entry

- Prepare class
  - Educate peers about classmate's disease
  - Give opportunities to ask questions about the child and the disease
  - Encourage classmates to visit the child at home or in the hospital

# Changing expectations for school

- With children getting more of their care on an outpatient basis
  - more home and family involvement
  - Homebound instruction
  - Flexible school days
  - Use of technology
- Shaw & McCabe (2008)

# Resources

- Clay, D. (2004). *Helping school children with chronic health conditions: A practical guide*. NY: Guilford
- EDMedKids Project (Wodrich, Aros-O'Malley, & Tesoro , 2013) <http://www.edmedkids.arizona.edu>
  - Website created for teachers but can be used by school psychologists to support and help disseminate information to teachers working with students with chronic illnesses.
  - Information about returning to school after illness
  - Common classroom problems
  - Toolbox included with reproducible forms
  - Links to additional online resources



# Type 1 Diabetes in Schools

By: Elana Dumont, MA, MS

# Introduction

- **Definition:**
  - Type 1 diabetes (T1DM) is an autoimmune disease in which the pancreas does not produce insulin
  - Insulin is the necessary hormone that converts sugar, starches, and other food into energy
  - Glucose accumulates in the bloodstream and the urine while the body draws on other sources of energy

# Prevalence

- Diabetes affects over 215,000 youths under the age of 20
- About 1 in every 500 children & adolescents has Type 1 diabetes
- Type 2 diabetes, previously considered a disease of older adults, is now on the rise among children and adolescents

National Diabetes Fact Sheet (CDC, 2011)

Wodrich et al. (2011)

# Symptoms of Diabetes Onset

- Fatigue
- Thirst
- Hunger
- Frequent Urination
- Weight loss

# Management

- Individuals with T1DM must adhere to a specific regimen including frequent testing of blood glucose, insulin management, and diet and exercise
- May require multiple daily injections of insulin or insulin delivered through an insulin pump to maintain normal blood glucose and prevent further complications

# Hyperglycemia

- High blood glucose. Occurs when the body does not have enough insulin to process the glucose in the body
- Common signs: frequent urination and increased thirst
- If excessive may lead to ketoacidosis signaled by:
  - Nausea and vomiting
  - Dehydration
  - Stomach pain
  - Deep and rapid breathing
  - If not reversed can lead to coma or death
  - In mild, but chronic forms may result in retinopathy, neuropathy and nephropathy
- Hyperglycemia can be treated by administering insulin

# Hypoglycemia

- Low blood glucose. Occurs when the body has too much insulin .
- Common signs: feelings of shakiness, dizziness, sweating, headache, blurred vision, hunger
- In more severe states
  - fainting, loss of consciousness
  - seizures
- Hypoglycemia can be treated with fast acting glucose, such as juice or candy, to quickly raise blood glucose levels

# Glucose Maintenance

- Due to complex treatment regimen, it is not uncommon for a child to experience wide fluctuations in blood glucose levels during the day in response to:
  - The time, type and dose of insulin administered
  - Time and type of food eaten
  - Amount of exercise
  - Stress and illness can further affect the body's need for insulin

# Cognitive Functioning

- Since proper glucose metabolism is crucial for brain development and functioning, diabetes may be considered a risk-factor for learning disorders (Sandberg & Barrick, 1995)
- Abnormal (high or low) blood glucose concentrations can lead to temporary or even long-lasting changes to CNS functioning
- Children with T1DM, particularly those with poor glycemic control, are prone to neuropsychological deficits (Lin, A., Northam, E.A., Rankins, D., Wether, G.A. & Cameron F.J., 2010).

# Cognitive Functioning

- Inconsistent findings regarding the impact of T1DM and cognitive functioning
- Most research has been with adults
- In children, two factors impact cognitive functioning:
  - Age of onset of diabetes
  - Severity of hypoglycemia/hyperglycemia

Patino-Fernandez, A.M., et al. (2010)

# Cognitive Effects in Adults

- Hypoglycemia
  - Decrements in decision making, sustained attention and mental flexibility
  - Transient memory impairments
- Hyperglycemia
  - Speed of information processing, working memory and some aspects of attention are impaired during acute hyperglycemia

# Cognitive Effects in Children

- Even mild hypoglycemia results in impaired performance on tasks requiring planning, decision making, attention to detail, visual scanning or rapid responding (Ryan et al, 1990; Wysocki et al, 2003)
- children exhibit deficits of attention as a result of blood glucose fluctuations, despite normal intellectual abilities (Wodrich et al, 2011; Parent et al, 2009)
- With children, an important finding is that many of the effects on neuropsychological tasks are seen in mild or asymptomatic levels of hyperglycemia
  - Often preceded physical warning signs
  - Delays seen in return to normal cognitive functioning for up to an hour after glucose levels had returned to normal range
  - At these levels even an alert teacher may not notice child having an episode. Need to take preventative steps

# Effects on Learning

- Cognitive effects of hypoglycemia are transient
- However, if mental efficiency is repeatedly reduced for significant periods, the child may be less attentive to classroom activities and miss out on learning opportunities
- Research is unclear as to whether repeated episodes of hypoglycemia lead to cumulative or enduring cognitive deficits

# Cognitive/Academic Functioning

- children with an earlier onset of T1DM have higher rates of learning problems in the areas of reading, spelling, and math (Hannonen et al, 2012)
- Meta-analysis indicated that children with diabetes perform lower on writing, reading and verbal tasks than children without diabetes (Naguib et al , 2009)

# Attendance

- T1DM impacts children's school attendance, peer relations at school, and classroom behavior.
- Average 14 days per year
- Even students with T1DM who have consistent school attendance, miss out on classroom instruction for reasons such as, leaving to eat a snack, checking blood glucose, or injecting insulin
  - (Kucera & Sullivan, 2011; Wodrich et al, 2011)

# Social and Emotional Functioning

- Adolescents with T1DM are at an increased risk for psychological disorders, such as depression, anxiety, and eating disorders
- Jaser et al. (2012) found that 17% of a sample of young adolescents had clinically significant symptoms of depression
- Depressive symptoms are associated with elevated HbA1C levels and poorer adherence (Sacco & Bykowski, 2010)

# Social and Emotional Functioning

While many children and adolescents with T1DM are at risk for psychological disorders, many engage in successful diabetes self-management and are in good glycemic control (Hilliard et al, 2012).

-little research available on how positive attributes such as resiliency and life satisfaction impact school functioning and glucose control in youth with T1DM

# Protective factors

- Positive attributes, such as resiliency and quality of life is related to school grades and glucose control (Perfect & Jaramillo, 2012)
  - Resiliency includes components such as mastery over one's environment, adaptation, optimism, and feeling supported by others
  - Students who saw themselves as being capable of overcoming adversity, had a positive outlook, and reported fewer diabetes-related stressors were more likely to perform better in school
  - Individuals with higher levels of self-mastery also had positive parental reports and parents were less concerned about their child's attendance, relationship with teachers, and interest in school

# School related concerns of parents and teachers

Pinelli et al. (2011) identified challenges, concerns, and needs of students, their parents, and teachers.

## Parents:

- Concerns regarding child's difficulty concentrating, difficulties with meals, and lack of enthusiasm and motivation in school because of their illness
- Difficulties with school staff, including checking blood sugar, administering insulin, lack of knowledge, and attitude of school personnel
- Difficulties with schools when needing to store glucagon
- Hesitation in discussing these issues with teachers, as teachers may think they are using their child's illness as an excuse for their performance

## Teachers:

- Less than half of the teachers reported having received any training in T1DM
- Teachers were unaware how to react in a hypoglycemic episode
- Of those that received training, majority reported it had been from the parents of children with diabetes

# School related concerns of students

- Overall, results indicated that children were satisfied with the support and help they received from nurses, teachers, and friends
- However, they were not satisfied with the help they receive from adult leaders in after school activities
- For example, they reported that coaches are not able to attend to diabetes complications at the same time as coaching a team

Lehmkuhl & Nabors (2007)

# Role of School Psychologist

- Work with school staff to promote diabetes education
- Be aware of and prepared to provide support to the emotional needs of students with T1DM
- Promote independence and self-care
- Communicate with teachers and school nurse

# Parenting Stress

- Responsibility of the child's daily diabetes management increases stress in parents of children with T1DM
- One third of pediatric parenting stress is related to parents' beliefs about their ability to manage their child's regimen, feelings of responsibility, and fear of a hypoglycemic episode

Streisand, Swift, Wickmark, Chen, & Holmes, 2005

# Parenting Styles

- Parenting styles, involvement and diabetes monitoring by the parent impacts treatment adherence in children with T1DM
  - Parenting styles defined by comfort, support, and structure for a child with T1DM is related to better adherence, glycemic control, and quality of life in youth with T1DM
  - Strict and restrictive parenting styles are related to worse adherence and glycemic control

Palmer et al., 2010; Botello-Harbaum, et al., 2008; Davis et al., 2001; Butler et al., 2007)

- In general children with T1DM are better able to manage their diabetes when they have a supportive family atmosphere (Cohen et al., 2004).
- Sometimes increased parental involvement may cause parent-child conflict (Guo et al., 2011)

# Future Research

- My research project examines the relationship between parental stress in caring for a child with T1DM, different parenting styles, and parental perception of their child's compliance with their regimen
- I hope to gain a more in depth understanding of parental stress related to having a child with a chronic illness and how that may be related to different parenting styles
- This information will help inform interventions with parents and improve parent-child relationships specifically with regards to chronic illness

# Diabetes Resources

- American Diabetes Association
  - [www.diabetes.org](http://www.diabetes.org)
- Lifeclicnic
  - [www.lifeclicnic.com/focus/diabetes/childrenteen\\_main.as](http://www.lifeclicnic.com/focus/diabetes/childrenteen_main.as)
- Children with Diabetes
  - [www.childrenwithdiabetes.com](http://www.childrenwithdiabetes.com)
- Diabetes Living
  - [www.diabetesliving.com/kids/kds\\_schl.htm](http://www.diabetesliving.com/kids/kds_schl.htm)

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