Chronic Illness and School Reintegration: How We Can Help

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Objectives

• Define chronic illness
• Increase awareness on the lack of preparation and training for school personnel when working with students and families with chronic illnesses
• Identify components of a successful school reintegration program and ways to recognize and utilize additional resources
• Introduce ways to maintain a presence with the school after a school reintegration
Do you work with or live with a child who has a chronic illness?
What is Chronic Illness?

• Health problem that lasts over 3 months
• Affects child’s normal activities, may require multiple hospitalizations, possible home health care involvement
• Estimated that 15-18% of children in the US live with a chronic health condition
Types of Chronic Health Conditions

- Asthma
- Diabetes
- Cerebral Palsy
- Sickle Cell Anemia
- Cystic Fibrosis
- Cancer
- Seizures
- Spinal Bifida
- Heart Problems
- ETC.
Austin’s Story (Video)
Side Effects for Pediatric Patients

- Unusual or easy irritability
- Change in ability to pay attention
- Change in sleep habits
- Sad or depressed mood
- Loss of interest in favorite toys or activities
Cognitive Effects

- Memory during lectures/assignments
- Learning ability regarding material
- Reasoning with peers and teachers
- Speed of mental processing
- Attention or concentration
- Difficulty understanding speech or writing
- Difficulty speaking or writing
- Inability to organize thoughts and ideas
- Trouble following conversations
Social Problems

- Trouble with turn taking or topic selection
- Problems with changes in tone, pitch or emphasis to express emotions, attitudes or subtle differences in meaning
- Difficulty deciphering nonverbal signals
- Trouble reading cues from listeners
- Trouble starting or stopping conversations
- Inability to use the muscles needed to form words (dysarthria)
Behavioral Problems

- Difficulty with self-control
- Lack of awareness of abilities
- Risky behavior
- Inaccurate self-image
- Difficulty in social situations
- Verbal or physical outbursts
Emotional Problems

- Depression
- Anxiety
- Mood swings
- Irritability
- Lack of empathy for others
- Anger
- Insomnia
- Changes in self-esteem
Effects on Development

• Executive Functioning
  ➢ Problem-solving
  ➢ Multitasking
  ➢ Organization
  ➢ Decision-making
  ➢ Beginning or completing tasks

• Sensory Problems
  ➢ Persistent ringing in the ears
  ➢ Difficulty recognizing objects
  ➢ Impaired hand-eye coordination
  ➢ Blind spots or double vision
  ➢ A bitter taste, a bad smell or difficulty smelling
  ➢ Skin tingling, pain or itching
  ➢ Trouble with balance or dizziness
I keep it all to myself.

THE STRONGEST PEOPLE ARE NOT THOSE WHO SHOW STRENGTH IN FRONT OF US BUT THOSE WHO WIN BATTLES WE KNOW NOTHING ABOUT.

"You never know how strong you are until being strong is the only choice you have."

-Bob Marley
Are You Stressed??
Background

• Gap in services between hospital and school
• Lack of funding for local school reentry program
• Wanted to identify:
  ➢ Where were school counselors at with their understanding of chronic illness?
  ➢ What did they need to know?
Effects on School Counselors

- Frequency of students reentering school following hospitalization from chronic illnesses continues to increase (Martinez & Ercikan, 2009).
- Knowledge and training when working with students with disabilities is lacking (Milsom & Akos, 2003).
Research Questions

1) To what extent are school counselors prepared to work with children with chronic illnesses reentering school following hospitalization?

2) What are the educational/training needs of school counselors when working with students with chronic illnesses returning to school following hospitalization?

• Surveyed all currently practicing and credentialed ND school counselors who had access to the NDSCA listserv
Results

• Preparation
  ➢ Strategies to facilitate coping: 77% “NO”
    • Adequately prepared them to work with students diagnosed with chronic illnesses: only 2% (n = 1) strongly agreed
    • Adequately prepared them to work with students reentering school after extended hospital stays: 19% (n = 12) strongly disagreed, 32% (n = 20) somewhat disagreed
    • Provided adequate information on ways to help a student understand his/her chronic illness: only 2% (n = 1) strongly agreed
Results continued

• School Environment
  - Made aware of side effects and treatment: 56% somewhat agreed
  - Familiarity with resources: only 53% somewhat familiar
  - Awareness of trainings on therapeutic interventions: 38% slightly aware, 30% not at all aware

• School Reintegration
  - Services to prepare a classroom: only 10% were extremely aware of services
  - Adequate training to educate student’s classmates: 22% somewhat disagreed, 10% strongly disagreed
Results continued

- School Reintegration
  - Aware of available services to prepare school population: 56% “NO”
  - Suggestions participants made:
    - Collaboration between school and medical personnel
    - Trainings and breakout sessions at conferences
    - Access to websites regarding strategies and tips
  - 44% indicated “YES”
  - Services they found helpful:
    - Making referrals
    - Utilizing outside agencies
    - Contacting local hospitals
    - Increasing communication between parent, student, school and medical community
Results continued

• School Reintegration
  - Information on side-effects: 81% “YES”
  - Made aware of trainings on:
    - Chronic illness: 76% “NO”
    - Students returning to school following hospitalization: 85% “NO”
  - Taken trainings on:
    - Self-worth: 29%
    - Behavior: 29%
    - Physical Appearance: 16%
    - 67% had taken no trainings in these three areas
Significance

- Research (ND school counselors):
  - 86% have worked with 1 or more children identified as reentry students
  - 77% stated “no” when asked if graduate programs discussed strategies to facilitate coping with this population
Nuts and Bolts

• History of Sanford Children’s School Reentry
• Components of the Program
• Population Served
• Issues with Funding
Oh the places we’ve been....
Current Strategies

• Hospital tutor services
  ➢ *Working with and assessing child prior to discharge*

• School Reintegration
  ➢ *Explanation for children AND staff*

• Coordinated Treatment Centers
  ➢ *Late Effects*
  ➢ *Cerebral Palsy*
  ➢ *Cystic Fibrosis*
  ➢ *Traumatic Brain Injury*
  ➢ *Downs Syndrome*
School Reintegration Program

• What is it? How did it happen?

• How do we treat it?
  ➢ Surgery
  ➢ Tests
  ➢ Medicines
  ➢ Therapies

• Continued treatment?
  ➢ Hospital/clinic follow-up
  ➢ Medicine
  ➢ Therapies
School Reintegration Program continued

• Points we address
  ➢ *Is the child different?*
  ➢ *Can you catch it?*
  ➢ *Side effects?*
  ➢ *New, special accommodations?*

• Monkey in My Chair
  ➢ *Program for oncology patients*
School Reintegration Program continued

• What can friends/classmates do to help?
  ➢ *Keep them connected*
    • Send cards, letters, pictures, email, text, social media, Facetime, Caringbridge

• What can friends/classmates do to help?
  ➢ *Offer to carry books*
  ➢ *Offer to help with school work*
School Reintegration Program continued

• Meet with teachers/staff and parents/guardians
  ➢ Address concerns
  ➢ Provide recommendations
    • Need 504 plan, IEP?

• Provide contact information for future questions
Strategies for Improvement and Collaboration

- Increased presence/collaboration with schools
- Contacting school counselors/administration
  - ROI
  - Professional Development/trainings
- Advocate for the child’s needs! What needs to be adapted?
- Continued follow-up
  - DOING MORE
Strategies for Coping

• Join a support group
• Journaling
• Assist parents and school with setting a structured routine
• Allow time for “brain breaks”
• Adapt work expectations or tasks to fit child’s needs
• Create a supportive learning and home environment that doesn’t overstimulate
• Provide “fidget” items as needed
Conclusion

• Many families are affected by chronic illness
• Lack of education for school counselors/personnel on how to work with children who are affected by chronic illness
• Appears to be a strong need for experience, preparation, and implementation of programs on school reintegration
Take Away……

• **EVERYONE** needs to work together to help children with chronic illness succeed!!
QUESTIONS?
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You treat a disease, you win, you lose.
You treat a person, I guarantee you, you'll win, no matter what the outcome.
References

Mayo Clinic – Mayoclinic.org


