

The Academic Journeys of Students with Chronic Gastrointestinal Illness:
Narratives from Daughters and Their Mothers

Taunya Wideman-Johnston

Nipissing University
taunyarose@yahoo.ca

Abstract

Today, more and more children and adolescents are surviving illnesses. There are also increases in outpatient care and continuous technological advancements, as compared to past decades. These changes give students with chronic illness greater opportunities to attend mainstream schools. The rising integration of students with chronic illness into the school setting requires educators to aptly accommodate students while the students pursue their academic journeys. This qualitative research study involves three case studies portraying students with a rare gastrointestinal chronic illness. In each of the three cases, the students and their parents were interviewed separately. The interviews focused on both the student's and mother's perceptions of the educational community's response to the student's needs. Implications rising from this study highlight how educators can work to adapt the school environment so that students with a chronic illness can better achieve their academic goals.

Introduction

The enrollment of students with chronic illness attending mainstream schools is continuing to rise, contributing to the growing need for research in the lives of students with chronic illness (Asprey & Nash, 2006). Increases in surviving life-threatening and life-limiting illness, increases in outpatient care, and increases in technological advancements are all factors contributing to the increased enrollment of students with chronic illness (Asprey & Nash, 2006; Martinez & Ercikan, 2009; Shaw & McCabe, 2008). Despite these noted increases in enrollment, identifying the exact prevalence of students in classroom settings with chronic illness continues to be a challenge for researchers as there is no static definition of what constitutes a chronic illness.

Literature Review

Researchers suggest that between 10– 30% of students have a chronic illness (Asprey & Nash, 2006; Clay, Cortina, Dennis, Cocco, & Drotar, 2004; Lynch, Rena, & Murphy, 1992; Martinez & Ercikan, 2009). For the purposes of this study, a chronic illness is being defined as “a medical condition of extended duration that creates impairment in adaptive behaviour and socially defined roles” (Shaw & McCabe, 2008, p. 74). The adaptive behaviours chronic illnesses affect include communication, self-care, academic performance, and motor behaviours. The socially defined roles impaired by a chronic illness can include social relations, roles within the family, schooling, and communication with medical and psychological professionals (Shaw & McCabe, 2008). In this study, I focus on the school experiences of three females with a rare gastrointestinal disease known as the motility disorder, Diffuse Irritable Gastrointestinal Tract Syndrome (DIGITS). DIGITS is an advanced form of irritable bowel syndrome that severely affects the bowel as well as several different locations in the body (DIGITS, 2013). The medical interventions the students require as a result of DIGITS are described herein. An ileostomy is a surgically created

opening into the small bowel through the abdomen. The intent of an ileostomy is to allow stool to bypass the colon (Hollister, 2003). The implications of having an ileostomy with DIGITS is regular dressing changes, frequent bathroom needs, hydration needs, and physical limitations. A peripherally inserted central catheter (PICC) is an intravenous that is inserted peripherally, usually in the arm. The catheter is long and advanced up the arm until the tip of the catheter is in a large central vein. The PICC line is used for patients who require long-term intravenous use. A hickman catheter is a central venous catheter inserted beside a large vein in the neck to permit intravenous use (London Health Sciences Centre, 2009). The implications of having a PICC or a hickman with DIGITS include physical restrictions, hydration concerns, nutritional needs, infection control, recreational limitations, and time constraints. DIGITS has only been defined since 2010, and research investigating this chronic gastrointestinal illness is limited. Exploring and understanding the medical implications of DIGITS is greatly needed, but it is also important to investigate the daily effects of living with DIGITS. Since DIGITS primarily affects young women, the specific schooling experiences of this population are important to consider.

There are many different ways in which students with chronic illness can be supported throughout their academic journey. Regular school attendance is important to providing normalcy by maintaining structure and routines in the lives of both children and adolescents. Attending school extends beyond academic achievement and can also promote stronger peer relationships, socialization, academic success, and more confidence in self-identification (Wilkie, 2012; Worchel-Prevatt et al., 1998). Thies (1999) identifies the stress students with chronic illness may experience from frequent absences by revealing, “Catching up takes time away from keeping up” (p. 395).

Theoretical Framework

Identifying a standard framework for accommodating students with chronic illness remains to be a challenge for parents, educators, and the medical community, as each individual with a chronic illness varies in how he/she will adjust to the chronic illness (Repetto et al., 2012). Adjusting to life with a chronic illness can depend on the age of the individual when diagnosed and on his/her cognitive and physical maturity during any given stage. Specific needs can also vary between students with chronic illness, since their management of symptoms, prevention of complications, and promotion of health can all be different (Thies, 1999; Thies & McAllister, 2008). Researchers from countries outside of Canada are exploring the experiences of students with chronic illness, their parents, and how their education system provides accommodations (Repetto et al., 2012; Shaw & McCabe, 2008; Wilkie, 2012). The limited research in Canada (Boyce et al., 2009; Martinez & Ercikan, 2009) on this subject reveals the need to investigate further the stories of students with chronic illness and how the Canadian education system is accommodating students with chronic illness.

Methodology

This study seeks to draw attention to the unique perspective and experiences of being a student with a rare chronic gastrointestinal illness, DIGITS, while pursuing an education, as well as to develop an understanding of the perspective and experiences of the mother of that child with a chronic illness. More specifically, throughout this study, I am investigating: (1) The issues that prevent students with chronic illness from achieving their educational goals; (2) How chronic illness affects the relationship between children, parents, and educators as it pertains to enhancing the educational pursuits of children with chronic illness; and (3) The coping methods used by individuals with chronic illness as well as their parents.

The study uses a qualitative methodology whereby individuals create their own social reality consisting of different meanings and interpretations (Borg, Gall, & Gall, 2005). A phenomenological life history approach is used to illuminate the lived experiences of the students with chronic illness and their mothers as phenomenological life history investigates the experience of the participants with the belief that, “To understand the many, we have to look intensively at the few, or even one” (Ungerleider, 1985, p. xv). The phenomenological method of the study is intended to illuminate the details of living with a chronic illness and how individuals perceive their reality with an emphasis on personal perspectives and perceptions (Husserl, 2002; Johnson & Christensen, 2012; Lester, 2009; Merriam, 2009). The aim of this study is to gain insight and understanding from the participants’ subjective motivations, actions, and experiences. Using life histories as a method of the research study provides participants

the opportunity to share their perceptions without too much influence by the researcher. Denzin (1970) describes the purpose of life histories as an opportunity for a person, a group, or an organization to share their interpretation of experiences and definitions. Once the perceptions of the individuals are revealed, the researcher is able to begin to understand the individual's feelings and motivations for past and present behaviour (Denzin, 1970).

Participants

The research study included six participants in total. Three of the participants were female students with the chronic gastrointestinal illness DIGITS and three participants were the mothers of these children. Student participants varied in age from 19-25 years old and they had each been living with DIGITS for approximately seven years. Two of the students were currently pursuing postsecondary education and one student recently had graduated from secondary school. All of the student participants had been diagnosed with DIGITS. One student had an ileostomy, one student had a PICC line catheter, and one student had a Hickman catheter and ileostomy. London Health Sciences Centre (2010) defines DIGITS as:

Motility disorder(s) of the intestines (bowel) are diseases in which the intestinal muscle or nerves controlling the intestinal muscle do not work properly. The contents of the intestine (food or stool) cannot be moved along the intestinal channel, so the bowel is effectively blocked even though there is no physical kink or twist.

The mother participants varied in age from 47-52 years old. One of the mother participants was married, one was in a common law relationship, and one was single. All of the mother participants had one other child, and they were currently employed full-time.

Data Collection

There were six interviews in total, one interview with each of the students and one interview with each of the mothers. The students and their mothers each participated in a one-on-one, 45-minute interview, including both open-ended and fixed questions. Open-ended questions allowed the researcher to clarify a response or probe for additional information or clarification on an incomplete or brief response. There were a small number of fixed questions to gather data about the age and sex of the participants. The interview questions focused on how the individual with a chronic illness was achieving her educational goals. It also focused on the mothers' perceptions of their children's interaction with the educational system.

Data Description and Analysis

To interpret the collected data, I read and became familiar with the potential themes using the original interview questions as a guide throughout the data, examined the data seeking detailed descriptions of the participants and setting of the interview, categorized and coded the data to develop classifying themes in participant answers, and interpreted and synthesized the data to formulate conclusions and understanding based on high- and low- frequency answers (Gay & Airasian, 2003). The data reflected the similarities and differences between student and mother responses. If I was unable to answer the research questions from the data collection, possible explanations as to why the limitations occurred were investigated.

Findings

By sharing their stories, the students with chronic illness and their mothers revealed the need for further accommodations in the school setting in relation to the obstacles and barriers living with a chronic illness had caused. The four central recurring themes based on the experiences shared by the student participants included: physical limitations, psychological comparisons, social isolation, and academic implications. The central theme present in the mothers' responses were concerns related to the maintenance of their children's health and the hardships involved in having their children live with a chronic illness. The themes identified by both the students with chronic illness and their mothers exposed how living with a chronic illness affected all areas of one's life. In

pursuing their academic journey, these students encountered barriers that extended far beyond their academic achievement.

Physical Limitations

Identifying the negative impact of physical symptoms on schooling experiences is not an uncommon complaint for individuals diagnosed with a chronic illness. Symptoms students experience may be a direct result of the illness itself, but they may also result from medication(s) the student has been prescribed to help manage the illness. For the three student participants in this study, the symptoms of DIGITS included symptoms in the esophagus, stomach, small and large bowel, and bladder. The physical implications of having a gastrointestinal chronic illness that were identified by the students in this study included difficulties with pain, nausea, vomiting, constipation, overall exhaustion, and physical limitations. Participating in schooling activities was very difficult with the presence of these symptoms. For instance, needing to spend much time in the bathroom, experiencing physical pain, and not being able to eat sufficiently, all affected the students' schooling experiences. One student revealed the constant day-to-day fatigue associated with a chronic illness:

Usually before school it was a struggle. I'd get up in the morning, and I'd feel horrible and I'd fight with my mom about it. She'd want me to go, but I didn't want to go because I was feeling so awful. Then I would get there, and I would struggle to get through the day. By the time I got home I'd be like dead, couldn't do anything couldn't think. (Student 1)

Another student described the exhaustion she felt throughout the day and the physical limitations she encountered while attending school.

Sometimes I'm just so tired that I just don't know how I am going to get through the day . . . There are certain activities a) that happen in the morning so I can't make them or b) require physical strength. I can't lift anything cause of the PICC line and everything like that and I am also have to be careful because if I sweat a lot I am going to tire myself out very easily so if I lose a lot of water I can't get it back easily. So there are a lot of things I would love to do like I don't know play games, you know, go and workout. I used to love working out and I can't do it anymore because it's a safety hazard; I just cannot participate. (Student 2)

The motility disorder symptoms directly impacting the gastrointestinal tract affecting the bowel function resulted in extreme physical symptoms and much discomfort. As the student explained:

I have a lot of nausea, vomiting, and constipation . . . I would say the most common thing is tired because I am usually expelling so much fluid that I am not getting a good night's rest. (Student 3)

The individuals in the study clearly identified the numerous physical symptoms DIGITS had on their day-to-day life in pursuit of attending school. The physical requirements of attending school were extremely difficult for these students. Students described the feeling of being too unwell to attend school, the energy and physical strength required to participate, and how the physical gastrointestinal symptoms of DIGITS interfered with the students' abilities to engage in daily schooling activities as consequences of living with a chronic illness. The physical limitations experienced by students with DIGITS affected all of their schooling activities from getting up in the morning and getting ready for school, to attending school, to the exhaustion that accompanied them at the end of the school day.

Psychological Comparisons

The psychological aspects involved with students having a chronic illness impacted how they thought and felt about who they were as individuals in comparison to their healthy peers. Student participants expressed the difficulties in their lives of having chronic medical symptoms and how these physical effects permeated into other areas of their lives including their emotional states. One student participant shared how living with a chronic illness differed in comparison to an acute illness that only lasted for a brief period in time. In this excerpt, a student explained the difficulty she felt in trying to express her thoughts and emotions about the symptoms of her illness.

Sometimes it's hard when you are not feeling good to go to school because it's not like I have the flu or a cold or anything that I can really share with other people. Because when most people aren't feeling well they can say I have a really bad cold. I don't really want to say that you know I have been up going to the bathroom all night or I have been vomiting. It's just not really socially acceptable to say those things. So I find that probably the most challenging thing and also when you are not up to par. For me it usually happens for long bouts of time so it kind of seems like you are the one getting everyone down because you are the one who isn't feeling well. Sometime it's just hard to keep up with a lot of your classmates with a lot of the other activities and recreational things that they do outside of school. It feels like you can't fit in and relate to everyone else in the class. (Student 3)

All the students revealed their inability to remain optimistic, especially in the instances when they were not feeling well or when the illness was at its worst. The students also described how living with DIGITS at home offered more freedom than living in a hospital setting, but there were still restrictions that did not allow for full participation in society.

I am not sick enough to be bedridden but sometimes I just lay and let time pass because I am just too much in it but at the same time I can't participate. There is so much I miss out on. I hate to do the "woe is me", but at the same time it's really frustrating because you want to be out there, you don't want to have pain, you don't want to worry about having to be home at a certain time to administer your meds or you are going to start like having a bad experience and stuff. But at the same time I don't want to be bedridden but, yeah, I definitely think life isn't as good as it could potentially be when you are sick. (Student 2)

The students also identified the need to stay motivated and engaged with life, so they did not lose touch with the world due to their illness. They identified how interacting with society through pursuing an education gave them goals and allowed them to feel they were part of society.

I also know what it is like when you don't have anything in your life and no commitments and no motivations or anything like that. (Student 1)

This is the only place I would be . . . I need to finish school . . . I definitely prefer grumbling and getting up than having nothing to do. (Student 2)

The psychological comparisons of living with DIGITS were unique to each student, but commonalities were evident in how all the student participants compared their states of health to that of their healthy peers. More specifically, they emphasized their struggles to share their symptoms to their peers, their concerns about always being the "sick" person, and their feelings of not having a fulfilled life. Each of these above descriptions reveals some of the psychological effects of living with DIGITS.

Social Isolation

All of the student participants revealed that their social lives were affected in some way by DIGITS. The dietary limitations from DIGITS contributed to uncomfortable feelings and experiences when interacting socially with peers. Students had a heightened awareness of not being able to eat what others were eating, and even more so when the student was not able to eat at all. One student described how uncomfortable she felt in social settings around food, which was problematic as many social gatherings include the consumption of food.

There is quite a bit of things I can't do. Eating is a very social activity and so a lot of times I can't do it, obviously in front of people. So to be at parties and things like that where everybody is eating pizza or something of course it is very awkward when people notice you aren't eating and of course everyone assumes you have an eating disorder. (Student 2)

The student participants also reflected on their difficulties in participating in required school activities with peers due to their frequent absences from school. Students shared how these absences contributed to their feelings of not being part of the school community.

Group projects were really difficult; I wasn't there so nobody really wanted to work with me . . . (Student 3)

In an educational setting, the most noted barrier to inclusion, according to the participants, was the social isolation that occurred as a result of having a chronic illness. Students felt they did not belong to the school community and were not members of their peer group. Their lives with chronic illness were very different compared to their healthy peers and this contributed to feelings of isolation.

I find my social life doesn't have anything in common; a lot of times I am really exhausted from just the day at school or the week at school so it feels like I don't do a lot of recreational stuff that a lot of people do over the weekend or at night time. Where I can't really share a lot of that stuff because a lot of the times I just sleep. (Student 1)

The social isolation endured by the student participants revealed the need for further education and understanding about what living with a chronic gastrointestinal illness, such as DIGITS, entails. When further knowledge is available to the school community, students with chronic gastrointestinal illness may not feel as isolated if others understand why they cannot eat, why their attendance is limited, and why they cannot always participate in schooling activities.

Academic Implications

Within the academic theme, all the student participants explained they had difficulty completing assignments on time and were regularly attempting to catch up on missed assignments. Each student participant described the constant, inevitable cycle of trying to keep the same pace as their healthy peers. They also reflected on the difficulties they encountered in attempting to stay caught up.

There are times when I do need extensions but I try to use them very sparingly. Like I don't want . . . like I know they are a backup but I don't want to have to use them. I want to play like everyone else; I want to make the cut-off. (Student 2)

Sometimes I was able to complete the deadline, and a lot of times I wasn't able to. It was difficult . . . it varied when I got sick. I had no control over it. (Student 3)

Mostly I disliked having to get caught up because I was away so much. It was really difficult to keep on top of things, and I'd finally get caught up, and then you'd be away again, and have to get caught up again. And everything was frustrating and harder to do. (Student 1)

I like working and I like working hard on projects and the achievement and like accomplishment of doing them. I just don't like doing them when I don't feel good . . . I would say that I usually or always need an extension at the end or at one point in the class I usually need some form of an extension. (Student 3)

All of the student participants described the continuous cycle of not being able to keep up with schoolwork as a significant stressor in their lives.

Parental Concerns

I think she doesn't find it user friendly [school] because of her experiences. It's more geared for the normal person it's not geared for when you have these challenges. And I think there's lots of room for improvement. I think it has to begin with the teachers and once the teachers are updated then or the school system I should say . . . it should come from the top down and once that is achieved then I think there will be a lot more children with chronic illnesses that will be accepted. (Mother of Student 1)

In an effort to protect their children, mothers may want minimal accommodations to ensure their children are treated normally. They might be overprotective, have unlikely fears, and they may not see their children's education as

significant (Worchel-Prevatt et al., 1998). All of the mothers shared similar themes in their interview responses. Their primary concern was for the overall wellness of their children. All of the mothers recognized the importance of their daughters pursuing education and attending school, but they did not appear to appreciate the barriers within the education system that their daughters were encountering while pursuing their education. The mothers all expressed the need for educators to acknowledge and respect the effects of the illness, and for educators to not see the chronic illness as a reflection of their daughters' academic abilities. The mothers all wanted fairness and equity for their daughters. The mothers focused on how proud they were of their daughters' achievements, but they also expressed how difficult it was to watch their daughters struggle to overcome obstacles while pursuing these academic achievements.

I find with [Student 3] she has had to work so much harder than anybody else. Because when she has to do a project and she is not up to par; she has the same timeframe as anybody else that has no chronic illness . . . not to be different or to have special rules but eventually teachers do have to find out about it . . . so once they realize she is a hard worker and she is intelligent and she is trying hard they also tend to give her a break and try to understand her situation. I find when she starts a new school year; it starts all over again because there are all these new people and she has to prove herself once more, and that's where I think it is very challenging for her. It's not so much having to tell them all it's the fact that she has to prove herself too. (Mother of Student 3)

All of the mothers revealed admiration for their daughters' work ethic and commitment to engaging in their academic endeavors despite obstacles faced within the educational setting.

She has to work three times as hard I think as someone who is just well and doing the work but she still enjoys it though and she learns quite a bit. (Mother of Student 2)

As well, all the mothers' expressed concern about the need for accommodations when their daughters were not feeling well enough to participate in schooling experiences. They felt the education system was not prepared with the knowledge necessary for understanding the implications of living life with a chronic illness.

I think when she is not feeling well . . . which shouldn't be used as an excuse but when she really isn't feeling well it would be nice if she would be able to stay home and have the work sent to her without actually having to participate in the classrooms considering. I don't think it is always necessary that you have to be there and she could get her lessons in other ways. (Mother of Student 3)

She was in and out of the hospital and then the surgery and things like that and so from grade 6 to grade 10 she would have missed 70 to 80 days a year of school, she still managed to pull off 70 to 75% average but it was like being on a tread mill, always catch up, always going to the teachers, "what did I miss?" . . . She didn't want to go to school anymore . . . she started to take online courses . . . She didn't get all her credits, like she wasn't able to graduate at the end of grade 12 year, so she did more online courses and then last year she went, she did what they say correspondence courses out of a book . . . She found the courses really challenging cause they had due dates. The due dates were specific sometimes she was too sick and was weak, needed an extra week, so she'd get behind and she didn't want to miss an assignment. She finished at the end of last year, good girl; sixth year she got her credits. (Mother of Student 1)

All of the mothers valued their daughters' education, but seemed to have difficulty comprehending that a limited understanding in the educational community about chronic illness existed. The mothers' visions and hopes for the lives of their daughters included seeing their daughters live with as little pain and stress as possible. As one mother revealed, her desire was to keep her daughter comfortable and at ease with life:

Making her more comfortable that's what we've been doing. Whatever you have to do you do and you do the best you can with what you have and enjoy every moment that you can. (Mother of Student 2)

Another mother identified the strength in her daughter that she admires:

I am very proud of her. . . She has made an awareness to everybody she touches and it's all in a positive light. (Mother of Student 3)

The mother participants were very involved in the lives of their daughters and knowledgeable of the impacts their daughters chronic illness. The love and admiration the mothers had for their daughters was clearly evident. The mothers witnessed, on a daily basis, the obstacles their daughters' health issues caused, and they did not see the need for schooling to contribute further to their daughters' hardships.

Discussion

This research study aims to identify the school experiences of students with the gastrointestinal illness, DIGITS, and their mothers. The themes that emerged from the data include physical limitations, psychological comparisons, social isolation, and academic implications. The aim of sharing the experiences and reflections of the three students who lived with DIGITS, as well as those of their mothers, is to aid educators in knowing what students with chronic gastrointestinal illness and their mothers need to ensure there is an opportunity for these young women to engage in their academic endeavors. With increased exposure to the issues faced by students with chronic illness, educators will hopefully be better informed regarding the daily struggles of these students, not only academically, but also physically, socially, and emotionally. Knowing how to meet the needs of students with chronic illness will also relieve fears during medical emergencies (Clay et al., 2004). It is important that students and parents are able to communicate their needs directly with educators to aid in fostering an optimal learning setting for students with chronic illness. The educational community needs to develop effective academic accommodations for students with chronic illness. Research suggests the constant feelings of a never ending workload can contribute to students not wanting to attend school at all (Thies, 1999). Suggestions for at-school accommodations can include: homebound instruction, flexible attendance, differentiated instruction, and distance education.

Parents of children with chronic illness are often fairly involved in their child's academic experience. To better understand parental perceptions, educators need to understand how the parents of children with chronic illness may be emotionally and psychologically affected. Parents may have certain concerns and may be apprehensive about their child participating in certain academic experiences.

Limitations

One of the limitations of this study is that the three participants all had dealt with the effects of the chronic illness for approximately seven years. All of the participants had multiple years to accept and adapt their lives to living with the daily impacts of the motility disorder. The mother participants identified how their children's ways of life had become their family norm as opposed to how it might be for a family with a child who had been recently diagnosed with a chronic illness. The students in this study have had years to learn how to live and adjust to life with their chronic illness. Issues that may have been obstacles when first diagnosed may have been forgotten or overcome. If the study had been conducted with students who had just been diagnosed with a chronic illness, the finding may have been different.

Educational Significance

Accommodating students with chronic illness requires a partnership between parents, educators, and the medical community. Repetto et al. (2010) suggest having further information available regarding the lives of those with chronic illness and how they are affected in the educational setting, as well as increased collaboration between stakeholders, and additional curriculum planning and accommodations for these students. Shaw and McCabe (2008) revealed 56% of parents of children with chronic illness shared that teachers do not have sufficient awareness and understanding about teaching students with chronic illness, and 75% reported the need for teachers to participate in specific training pertaining to students with chronic illness. Lynch, Rena, and Murphy (1992) acknowledged needs

for students with chronic illness that are not accounted for in the school system. Their depictions include funding, public and staff knowledge, available services, educational support, and homework accommodations. Additionally, teachers' misinterpretation of the child's needs and lack of knowledge about the illness are further issues that need to be fixed within the educational setting. Educators need to understand how the parents of children with chronic illness may be emotionally and psychologically affected, since educators will have repeated contact with parents. Recognizing the parents' emotions and opinions will aid educators' understanding as to why parents may be responding a certain way.

There are gaps in the literature in terms of identifying how students with chronic illness can be supported in the educational community to pursue their academic journey (Martinez and Ercikan, 2009; Maslow, Haydon, McRee, Ford, & Halpern, 2011; Shaw & McCabe, 2008; Thies, 1999). This research study fills this void in beginning to better understand the experiences, needs, and wants of both the students with chronic gastrointestinal illness and their mothers. This research study does not identify all of the needs and experiences of these students, but it does contribute to the body of literature regarding the experiences of being a student with the chronic gastrointestinal illness, DIGITS, offering some of their stories and perspectives.

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