SCHOOL TO HOME COMMUNICATION FOR THE IMMUNOCOMPROMISED STUDENT

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Marsha L. Fabian-Griffith

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SCHOOL TO HOME COMMUNICATION FOR THE IMMUNOCOMPROMISED STUDENT

AUTHOR: **Marsha Fabian-Griffith**

Jeanne M Dagna Ed.D.
Chairperson

Christopher C. Watt Ed.D
Committee

Committee

Sister Carol Anne Couchara, IHM, Ed D.
S. Carol Anne Couchara, IHM, Ed. D.
Professor of Education, Dissertation Support Manager
Director of Ed. D. Program

ON BEHALF OF IMMACULATA UNIVERSITY

M Parris Ed.D.	Melissa Reed, Ed.D.
Marcia Parris, Ed. D.	Melissa Reed, Ed. D.
Dean, College of Graduate Studies	Chair, Education Division

DATE: June 14, 2024

Abstract

The purpose of this study was to consider the school to home communication for students with compromised immune systems due to chronic illness. This study investigated the current level of communication between school and home/caregivers who support students with immunodeficiency disorders and who, due to their medical diagnoses, regularly miss school due to their illness/treatment/hospitalizations, etc. A nationwide survey was developed and administered via a website established for providing support to families with a member living with a primary immunodeficiency condition. In the survey, respondents were asked to respond to several statements with Likert scale responses. Multiple individuals volunteered for one-on-one interviews to obtain more information. In all, a total of 53 participated in the survey and 4 volunteered to be interviewed. The overall findings indicated that caregivers' perception of schools and their children's education were directly related to their perception regarding the quality and consistency of the communication between school and home, particularly about their children's medical and educational concerns. As a result of this study, more caregivers indicated an unfavorable experience with their children's school. The consensus was that the quality of communication, primarily frequency and transparency, had the greatest impact the research did not bear out one specific method, but did indicate that having one designated point person worked out most effectively for both the caregiver and school.

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Chapter One – Introduction

Overview

School to home communication has been a key component in students' success for decades (Bower & Griffin, 2011; Chittooran & Chittooran, 2010; Epstein, 1986). Multiple individuals can be considered as "caregivers" with respect to the child's home situation. For the purposes of this study, "caregivers" related to any adult that has a responsibility for the child that affects his/her home life. This included biological parents, step-parents, extended family members (grandparents, aunts or uncles, etc.), and hired child-care professionals (e.g. au pairs). There are several components with regards to best practice for instructors communicating with students' caregivers. One such item is that "the family is treated with respect and is involved in the decision-making and educational activities that affect their children" (Grant & Ray, 2019, p. 96). Another is that communication from school to home cannot be just for when problems have occurred. Ongoing communication also strengthens the bond between student caregivers and the instructor(s), which also sends a message to the students that the instructors are willing to go beyond the classroom to help them succeed (Stone, 2015). Instructors have a plethora of vehicles in which to communicate with the family. These include podcasts, video lessons/updates, and direct email, just to name a few. Many schools have utilized electronic platforms that give instructors the ability to place lessons, homework papers, calendars, and study guides directly on the Internet for ease of parental access. These include such software platforms as Schoology, Google Classroom, and Edmodo. With the variety available, it gives each instructor a wide range of possibilities in which he or she will feel the most comfortable, and therefore more likely to make it a part of their routine (Krambari et al.,2018).

Kraft and Rogers (2015) determined that when teachers share information with the students' caregivers, there is a natural rise in the students' success rates. Their study indicated that there was a 41% reduction rate in course credit failure at a high school when a weekly message was delivered to parents directly from the course instructor (Kraft & Rogers). However, Okeke (2014) found that with a rise in technology that benefits the instructor's ability to disseminate information, there is not necessarily an equal rise on the part of the students' caregivers to receive and interpret this information. Some parents, while expressing a desire to receive more information, do not always know how to get involved, or can be intimidated by the mechanisms that are used to disperse the information (Okeke, 2014). When both caregiver and teacher feel positively about the interaction and communication between both parties, though, there is a very positive correlation with expected or desired behaviors of the students in question (Minke et al, 2014).

It is even more vital, then, that the bond effectiveness of communication is strengthened for those households in which children of special needs reside. Kendall and Taylor (2014) stated that this populous group, which includes those students who are immunocompromised, has concerns that go far beyond the schoolhouse doors, but do not make what happens in that building any less important. Many families are in the developing stages of communication, particularly due to the fact that they have to spread their time among more disciplines (medical, financial, etc.) than other parents with children who do not possess significantly impacting medical health needs.

Many caregivers of special needs students have felt that the school staff might not fully understand the unique circumstances of their child, and therefore not communicate most effectively needed information to the home (Kendall & Taylor). As stated earlier, though, many families are in the developing stage of communication, particularly due to the fact that they have to spread their time among more disciplines (medical, financial, etc.) than other parents with well children (Scholten, 2018).

Need for the Study

This study is needed because immunocompromised diseases include a group of more than 350 rare, chronic disorders in which part of the body's immune system is missing or functions improperly, and a great many of the people with compromised immune systems are of school-age (Immune Deficiency Foundation, 2018). While not contagious, these diseases are caused by hereditary or genetic defects, and although some disorders might be present at birth or occur in early childhood, these disorders can affect anyone, regardless of age or gender (Immune Deficiency Foundation). According to the Immune Deficiency Foundation, some of these diseases affect a single part of the immune system; others may affect one or more components of the system, and while the diseases may differ, they all share one common feature: each result from a defect in one of the functions of the body's normal immune system. People with an immunocompromised condition live their entire lives more susceptible to infections--enduring recurrent health problems and often developing serious and debilitating illnesses.

Students in middle school and high school find themselves with greater responsibilities and higher expectations (Folayan, 2018). Coupled with having a Primary

Immunodeficiency, many of these students find themselves taking on even more responsibility than their peers as they learn to balance their medical needs and susceptibilities with these additional expectations. Primary Immunodeficiency (PI) is an inherited flaw in the immune system that increases one's chances of acquiring an infection, and there are currently 330 distinct disorders that fit this definition (Bousfiha et al., 2018). These needs can include: (a) frequent absenteeism, (b) not being able to commit to an extracurricular or academic study group, (c) teacher/peers asking about absenteeism, (d) falling behind on work, (e) taking IV medication, and (f) physical needs (Immune Deficiency Foundation, 2018). Students with PI may find themselves feeling more emotional and physical stress in a brick-and-mortar school setting (Sowers, 2018).

Medical statistics for Primary Immunodeficiency, such as hereditary and/or environmental factors are mostly non-existent because there are no screening devices available to test for these defects at birth, or even later in life (Kwan & Puck, 2015). According to the 2007 Immune Deficiency Foundation (IDF) survey, a PI diagnosis can take up to 12.4 years from the time symptoms begin to appear (Immune Deficiency Foundation, 2007). Due to the limited information regarding these medical conditions, students, parents and school personnel are often left uncertain on how to proceed. Researching and discovering ways to make these school to home interactions more positive is imperative (Immune Deficiency Foundation).

Statement of the Problem

There is ample research that addresses the need for communication between school and the homes of students to increase the likelihood of success (Young et al., 2018). The methodology and strategies utilized for school to home communication has grown significantly over the decades (Murray et al., 2014). These have crossed over multiple forms of media and have also shortened the pipeline between school and home by allowing parents and teachers to speak directly with each other without having to rely on the student as the intermediary. While these strategies have been effective, they have only done so as a generalization (Murray et al., 2014). The unique circumstances of immunocompromised children and their families require a more adaptive and comprehensive form of communication that will better allow all of the shareholders to work in harmony (Immune Deficiency Foundation, 2018).

Due to several factors, such as the increased numbers of affected students, combined with a general unawareness of educators, there is limited research on school communication with households of immunocompromised children (Blundell & Hine, 2018). The unfamiliarity of educators is not based on purposeful ignorance, but rather the previously-stated limited research and the subsequent lack of priority for professional development sessions specifically geared towards increasing educators' knowledge about the impact of medical diagnoses on their students (Blundell & Hine, 2018). The purpose of this research was to determine what communication methods are best for students with immunocompromising medical conditions, their caregivers, and educators.

Definition of Terms

504 plan – a broad federal civil rights law that protects all individuals with a handicap outlines services to be provided by the school district (New Hampshire Department of Education, 2018).

Antigens – any substance that causes the body to make an immune response against that substance (National Cancer Institute, 2018).

B cell – a type of white blood cell that makes antibodies; part of the immune system and develop from stem cells (National Cancer Institute, 2018).

Caregiver- a family member or paid helper who regularly looks after a child or a sick, elderly, or disabled person (Merriam-Webster, 2018).

IgG – the main immunoglobulin in human blood; contains long-term protective antibodies against many infectious agents (Immune Deficiency Foundation, 2018).

Immune system – complex network of cells, tissues, organs, and the substances they make that helps the body fight infections and other diseases (National Cancer Institute, 2018).

Immunocompromised – having a weakened immune system; patients have a reduced ability to fight infections and other diseases (National Cancer Institute, 2018).

Immunodeficiency- inability to produce a normal complement of antibodies or immunologically sensitized T cells especially in response to specific antigens (Merriam-Webster, 2018).

IV – means “within a vein”; allows medicine or fluid to enter the bloodstream right away (U.S. National Library of Medicine).

Lymphocytes – type of immune cells made in the blood marrow and found in blood and lymph tissue (National Cancer Institute, 2018).

Primary (congenital) immunodeficiency – chronic disorders in which part of the body’s immune system is missing or functions improperly; caused by hereditary or genetic defects (Immune Deficiency Foundation, 2018).

Secondary (acquired) immunodeficiency – occurs when the immune system is compromised due to an environmental factor (American Academy of Allergy, Asthma, & Immunology, 2018).

T cell – a type of white blood cell; part of the immune system and develop from stem cells; help protect the body from infection (National Cancer Institute, 2018).

Limitations

The researcher anticipated several limitations to this study. One such limitation is the respondents' knowledge and understanding of the terminology. This could have led to teachers improperly identifying or misidentifying students as being immunocompromised. This misidentification could also have led to parents not identifying or recognizing communication components already in place in their current school. Additionally, the terminology might have been foreign to younger participants, even though they have the condition. Based upon family choice or student age and ability, the student might not have been exposed to the particular medical terminology specific to their condition.

Another limitation was the instruments used to collect data from the respondents. These instruments might have incorrectly assumed a prior knowledge base for any one of the three respondent categories (student, caregiver, or educator). Students might not have been aware of how the condition will affect their bodies in future stages, caregivers might not have been aware of particular communication mechanisms, and educators might not have been cognizant of the physical manifestations of immunocompromised students, or the obstacles facing those families. Other limitations that could have occurred could fall under the categories of researcher bias, along with instrument validity and reliability. The researcher bias, specifically, could have resulted due to the fact that the researcher was a school teacher, and had a child who qualified as immunocompromised. It is reasonable to infer that some of the surveys and interviews would be skewed by the researcher's first-hand knowledge of medical and educational terminology, along with years of training and exposure. The limitations included the small population of respondents to this study, which means that this study's results cannot be generalized over a larger population or towards an area outside of Pennsylvania where the study occurred.

Research Questions

Based on the needs of students and caregivers in general, and immuno-compromised students and their families specifically, along with the needs of instructors to communicate effectively and assist with the families in meeting their needs, this study attempted to answer the following questions:

1. What factors do caregivers believe impact communication between the school and the home setting of students with compromised immune systems?
2. What tools and procedures can schools implement to ensure effective communication between the school and the home setting of students with compromised immune systems?

Summary

Educators and caregivers have both stated that fluid communication between the two is vital for student success (Bourke-Taylor et al., 2018). Educators are expected to notate not just learning progress through the use of gradebooks, but a variety of other student data, including behavioral patterns and executive function skills (Timmerman et al., 2016). Caregivers are consistently working with medical professionals to assess their child's physical concerns, and also need to mesh these concerns with their child's academic progress. It is only natural for caregivers to try and optimize their child's medical needs with their academic needs (Minney et al., 2018).

Previous studies have outlined that effective communication with the home has a direct correlation upon student success (Grant et al., 2019). With a plethora of new technologies, the potential for more communication between school and home exists. However, the rate of rise in technology has, in general, outpaced the learning curve of many home caregivers and educators (Tondeur et al., 2016).

By their very definition, immunocompromised diseases affect the body in a way that prevents it from forming needed defenses against the germs and viruses found in large populations and general settings; therefore, students who are immunocompromised face dangers everyday just by attending brick-and-mortar schools. This fact alone places immunocompromised students under more stress than their counterparts, physically, medically and academically (Sowers, 2018).

This study worked to identify improved communication components that assisted all of the shareholders comprising and supporting the student's educational experience. Specifically, the study identified communication components already in place, ones that can be implemented with little or no stress for the users, and perception and reality for those working with children who are immunocompromised. These types of communication tools allow for the sharing of information in "real time" and for issues/concerns to be addressed in a timely manner, not days later when the issue might be harder to address.

Chapter Two – Literature Review

Introduction

From 1990 to 2014, the number of students served under the Individuals with Disabilities Education Act (IDEA) rose from 4.7 million to 6.5 million. These numbers represent a range of approximately 11 to 14 percent of the total students enrolled in America’s public schools (National Center for Educational Statistics, 2016). Extrapolating that data would show that for every class of 25 students, a teacher would have an average of 2-3 students who qualify for special needs supports under IDEA. According to Goodall (2015) given these statistics, it would seem unreasonable, then, that a teacher should continue to deliver information in the same general way they did before the inception of IDEA in 1975.

This chapter will relate some of the teacher methodology for disseminating information, both from historical and modern perspectives. It will then specify the communication needs more directly related to those families with children who have special needs. Next, it will examine the various perspectives of educational needs for the teacher, caregiver, and student. These will include timely communication with common language between the parties, clear expectations with realistic goals and timelines, and transparency that doesn’t impair personal protections. Lastly, this chapter will identify and discuss the school-family communication needs that are specific to the child who is medically immunocompromised.

School to Home Communication: An Historical Perspective

In the earlier stages of school to home communication, teachers were primarily limited (Thompson et al., 2015) to two areas: a phone call or a note home (which was usually transported by a student). The downside to both of these were that they were limited to one person/parent at a time and also on the child's follow-through with the delivery of the note. This method meant that teachers usually only did this in case of something that was unique to that student's situation (Goodall, 2015). It made the communication strictly reactive. Caregivers were privy to information in small doses, and never consistently. The phone call (or note) home was usually done in reaction to something negative, which then naturally conditioned students and caregivers to view the school communication as something negative and unwelcomed (Bai & Repetti, 2018).

This type of communication was primarily passive in nature, as the only return expected by the teacher was a signature on a failed test, or perhaps a confirmation of receipt of the initial message. Oftentimes, there was also very little to no depth or context to the message (Goodall, 2015). It tended to be very superficial in nature, focusing only on the situation/outcome and not possible causes. This type of communication could be very detrimental to a family with a special-needs child, as the outcome exhibited by their child would not necessarily have the same genesis as that of a child without a diagnosed disability (Galloway, 2017). In the pre-Internet age, information was done (provided-shared) in chunks, and often lacked fluidity. An absence of cell phones meant that calls were restricted to an individual's proximity to said device. A lack of email meant that teachers were dependent upon students to get an important message home, or use the postal service for a message delivery time of several days. (Kielty, 2018).

Goodall (2015) posited that with whatever communication method was chosen, it was more difficult to establish a rapport and collaborative environment, as one-way communication was ill-fitting for both parties. Caregivers at home and teachers at school needed to find a more effective way to communicate that lessened the time for the message to travel one way, but also encourage reciprocation. Besides being compatible from a personality standpoint, teachers and caregivers find a degree of success in how their cultures and values match, how each views their roles, and the influence of society (Keyes, 2002). Effective communication was the key to relaying all of those pieces of information between the educational shareholders.

Schools began to become aware of this trend, and started to develop classroom newsletters (particularly in the elementary schools). This was done to disseminate information on a broader scale, and could provide information in both a positive and proactive manner (Grant, 2019). Newsletters provided an opportunity for teachers to highlight student achievement, alert parents to upcoming classroom/school events, and summarize general learning units. Carter, Greenburg, and Walker (2017) found that this same idea took hold even more dramatically in the Internet age when teachers from all educational levels began to see the value in mass-producing and disseminating information on a broader scale to all homes. Parents could access information about a class and/or teacher through a building- or district-sponsored webpage, with the same general information as the aforementioned newsletter (Epstein et al., 2018).

School to Home Communication: A Current Perspective

With the dawning of more fluid technology, teachers could now use technology to have an electronic presence that feels more interactive, rather than the one-sided 'presentation' style of yore (Gil-Flores, Rodriguez-Santero, & Torres-Gordillo, 2017). Gil-Flores et al. wrote that teachers can now post video lessons, with the option of viewer feedback and conversation. Podcasts are ways for students to find out what they might have missed in class that day if they were out sick, had an early dismissal, or were meeting with another staff member. Instructors can post handouts that were utilized in class, so students that misplace their copy can download and print a new one. Students and caregivers can message teachers directly, and have ongoing conversations which can span multiple days. This technology transfers the information from a one-way street to a superhighway of information (Olmstead, 2013). It has also allowed instructors to develop multiple ways to administer assessments, allowing students to demonstrate knowledge in a variety of ways (Koellner & Jacobs, 2014) and transfer that information demonstrated in the assessment more quickly back to the caregivers working with that student at home. These multiple pieces of information, including the use of ePortfolios instead of the traditional hard-copy, has been shown to increase parental confidence in their communication with the teacher and an increase in the positive perception of their child's educational experience (Higgins & Cherrington, 2017).

Communication does not just take place between the teacher and the caregiver. Recent technology has allowed the instructor to give more effective feedback to all students, and more effectively for the children with special needs (Goodall, 2015). One example is the ability to attach an electronic rubric to a piece of student work. This allows the immunocompromised child who might be home for an extended period of time does not have to wait for feedback from a recent project that might not arrive in a timely manner. Teachers can now hold electronic conversations with the whole class over a set period of time. These communication methods allow an immunocompromised child who is out for an extended period of time to engage with the class conversation, keeping their level of perceived connectivity at a higher rate, which might in turn raise their perception value of the educational process (Seki et al.,2016). According to Seki et al., if a student is unable to complete a writing assignment through written language (print or digital), the teacher has the ability to allow the students to submit an oral copy of their response through audio or video/audio files that can be directly transmitted to the teacher. The teacher can, in turn, post comments to the video to keep the at-home child engaged in the current happenings of the classroom. Although these methods might be directed primarily towards the student, the caregiver can also access these electronic conversations. This then increases the level of transparency between school and home, which naturally increases the perceived value of the school in the eyes of the at-home caregivers. As a direct corollary, this paves the way for more effective communication between school and home (Seki et al., 2016).

Regardless of the intended audience, Goodall (2015) holds that there is a disparity that needs to be addressed between school and home perspective. Many schools still operate on a passive scale, meaning that caregivers have to follow the school on social media or go to the school's website. This is still additional time spent by the user, and the caregivers of children with special needs generally do not have a plethora of additional time for this process (Immune Deficiency, 2018). Herold, 2018 determined that while 78% of school districts push towards just posting items on social media as effective, only 16% of caregivers agree that this is an effective way to share information. Schools and teachers should look at adjusting their methodology from a passive voice to an active one. Only 19% of caregivers would want to go to the school's website to find information, but almost 50% would prefer the latest information texted directly to them (Herold). However, this presents a dual-sided challenge to schools. While technology is widespread, there is no guarantee that every student and family within a district will have the electronic capability to receive information digitally. Kosaretskii and Chernyshova (2013) stated that there are many pockets of poverty that prevent schools from utilizing electronic communication as the sole method of disseminating information. Schools, then, must have a conduit to push out information to families across the electronic spectrum. By the same token, the teachers in these districts face the same challenges (Kosaretskii & Chernyshova, 2013).

School to Home Communication for the Families of Children with Special Needs

As discussed before, classroom teachers have modified their methods of communication over the years to increase the level of transparency from school to home. As teachers have done this, there has been a natural mentality that "more means better." While this might be true as a generalization, it does not hold true for all situations (Rogers et al., 2018).

In the particular case of children with special-needs and their families, the 'standard' information home might not provide all of the information necessary for a child with particular medical needs/conditions. Teachers must first recognize that an individual's knowledge is constructed through their personal experiences (Dotger, 2009). Rogers et al. (2018) posits that teachers should not be expected that their information contained within home communication will meet the needs of the special needs' families, unless the teacher has had some level of exposure and/or experience with that particular condition or situation. This absence of exposure is not due to a lack of empathy on the teachers' part, or an unwillingness to learn. Seki et al., (2016) found that "schools are ill prepared in terms of experience, knowledge, skills and attitudes because of the low incidence rate of childhood diseases" (p. 283). This lack of exposure can readily lead to a variety of misunderstandings with regards to what the child can be expected and capable of doing, both in and out of the classroom. In their extensive research, Johnson et al. (2015) determined that it can also be especially difficult to negotiate from an administrative perspective. If a school district does not fully understand a student's illness or diagnosis, then they could hand out penalties for excessive absences. For example, if a student is diagnosed as immunocompromised, and carries a symptom of high fevers, then the school might send that child home until the fever breaks. Rafferty et al., (2017) notes that if the fevers have been diagnosed by a physician, then the parent will not take the child to a physician's office, knowing that the fever is not indicative of something larger and possibly be exposed to other illnesses while there. The school district, in turn, could require a doctor's note for absences totaling over a specific threshold. The parents could then be penalized for unexcused absences. Johnson et al., stated that additionally, a school could also exercise the option to retain a student for missing an excessive number of school days. All the while, this could have been avoided with careful, deliberate understanding and communication on the part of the school. The idea of a school not being fully aware of medical conditions is not a shocking revelation. Over time, teachers have been shown to have a poverty of information with regards to the needs of students with chronic health conditions (Johnson et al.).

While Chu (2014) determined that it is vital for all families to have meaningful communication with the school, it is even more vital for families of special needs children to have this outlet. Caregivers need to not only know the academic needs of their children, but also if any medical symptoms have occurred throughout the course of the school day. Chu (2014) found that while there is no magic number as to the ‘when’ of communication, studies have shown that misunderstandings between parents and teachers have constrained the frequency and productiveness of overall communications.

It is also important to note that communication to the home should not just be solely in regard to academic progress. With children who have special needs, especially those who are immunocompromised, the need for medicinal communication is equally as important (Rafferty et al., 2017). Since different medications have different time-release schedules, some students take medications at school and others at home (Nahmias, 1995). School-based nurses must have a direct line of communication with the caregivers, especially when medications have changed or schedules are altered. Additionally, there is communication feedback with regards to in-class observational forms from teachers (Nahmias, 1995).

As a generalization, school to home communication for the students with special needs and their families must be flexible (Rafferty et al., 2017). This can relate to both the methodology and the content of the communications. It is key that the communication be consistent and cover a wide breadth of information, over time. Rafferty et al. (2017) also notes that caregivers will need to know their child’s reaction to new medications, how the student is adjusting physically to any medications or changes in diagnosis, and their ability to focus on the class material as they battle a personal life-changing or life-threatening illness.

Teacher Perspective of Working with Students with Medical Needs

As discussed earlier, a general education instructor can average two to three students in a class size of twenty-five who might be eligible for some educational modifications or accommodations (National Center for Educational Statistics, 2016). For self-contained classrooms, traditionally at the elementary level, this means that the teacher has to take more into consideration when planning the lessons. Needs, such as seating proximity, study guides, and adapted assessments and test modifications are the just the norm. Parsons et al. (2017) shows that educators at this level need additional time to adjust the physical layout, prepare specialized papers, and modify prepared curriculum exams and assessments to meet the students' educational needs and eligible requirements. In terms of communicating with the home, however, this can also be time-consuming. If the teacher is using a general means of communication (social media, newsletter, etc.), then there might need to be an additional layer of communication home for special-needs families, that of confidentiality. Primarily due to the Health Insurance Portability and Accountability Act (HIPAA) of 1996 (Cohen & Mello, 2018), a teacher could not list something just for a special-needs student on their general information platform. Therefore, the teacher will need to take additional time to have some form of specialized contact with the home. Since this example is from a self-contained environment, then there would be fewer contacts needed than a departmentalized secondary teacher (Lucero et al., 2018). However, elementary instructors usually have more student contact time than their secondary counterparts, and have fewer guaranteed planning minutes, according to Thessin (2015). This translates into more needed work outside of the teacher’s contracted day. Consequently, teachers need a form of communication that has a minimal impact on their day.

For secondary teachers, there is some overlap with the aforementioned elementary teachers, but also some issues unique to this level. Thessin (2015) shared that secondary instructors, as a generalization, will have four or five different classes of students throughout the day. Using a model of twenty-five students per class, this translates into 100-125 students per teacher. Averaging two to three students per twenty-five, this extrapolates to eight to fifteen special needs students for the regular classroom instructor. Thessin holds that it would be unreasonable to have the teacher contact fifteen parents for each class or assignment. It would also be unreasonable to ask the parents to keep track of phone calls from four or five different instructors for each class or assignment. Although secondary education instructors tend to have more planning time (Thessin), which also includes common grade-level planning time, adding a layer of eight to fifteen home contacts would still be overwhelming. For the teachers’ and caregivers’ sake, there needs to be a centralized communication where all teachers can provide input, which then delivers one summary message to the caregivers at home (Thessin).

Patten (2017) posited that from both an informational and logistical perspective, it falls to the school administration to ensure that both of these are managed in ways that satisfy the needs of the both the school staff and caregivers. Principals are in control of their teachers’ schedules, and need to ensure that their student-contact time is balanced against a block of time that allows teachers to effectively communicate with caregivers, particularly those in special needs families (Sterret et al., 2018). District administrators must also work with building principals to establish in-service training that brings to light medical concerns present in the student population (O'Malley et al., 2018). For example, only somewhat recently have staff members been tasked with training for students who might experience an anaphylactic reaction. Staff members now have to complete a yearly training on identifying someone having a reaction, and correctly being able to administer an epi-pen. As health concerns have increased and expanded, the districts have matched the expansions with added training sessions to meet their students' needs (Mazzer & Rickwood, 2014). Immunocompromised students should be afforded the same recognition.

Teachers also need to be able to communicate with the child with special needs, directly. Over the course of their careers, teachers have naturally played the role of counselor and empathetic listener. However, working with a child with special needs can present a unique set of needs and circumstances. Some educational experts have turned to medical professionals to find more positively impactful ways of working with students having medical needs. One of these methods is SBAR (Glasper, 2016, p. 1144):

- Situation – what is the problem
- Background – information to contextualize the problem
- Assessment – your clinical assessment and prediction
- Recommendation – what you think should happen

Glaspaer found that where many teachers get "stuck" is the 'background' portion of this acronym. Effectively communicating with a student having special medical needs means that the teacher must have the needed background information to present information to this student in a way that demonstrates cognition of and is responsive to his or her needs. Teachers are human, and can have their own traumatic experiences, which might lead to a psychological barrier that prevents them thinking about serious illnesses or death (Binnebesel & Krakowiak, 2012).

Young et al. (2013) found that one item that can skew the perspective of the teacher is when he or she feels as though the caregivers' perspective is radically different from their own. Most educators see the caregiver's role as being involved and helping the child with school work at home. However, there are more than a few educators who feel as though their responsibility is also to ensure the child arrives at school on time, and help solve any problems that arise at home involving the caregivers themselves (Young et al). Even for children who present with special needs, there can be a percentage of caregivers who are seemingly incapable of providing the necessary support structures to educators (Staples & Diliberto, 2010). Whether it means not ensuring that proper medication regimens are followed at home, school work is not checked, or organizational support is not provided at home, caregivers can sometimes be viewed as antithetical to the educational process (Bergeron et al., 2018). For students with special needs, it is even more obvious challenging for schools/educators when caregivers do not attend IEP meetings, respond to phone calls or emails from teachers or guidance counselors, or send the child to school without their proper medicinal regimen being taken at home (Barnard-Brak, 2016). Additionally, some literature crosses over concerns for all of the aforementioned shareholders. One such piece is the current idea of not vaccinating children due to a long-debunked article that tried to tie vaccinations to the occurrence of autism in children (Swan, 2015). Since the immunocompromised child is, by definition, more susceptible to communicable diseases, it follows that any kind of environment with an increase in exposure to communicable diseases is logarithmically more dangerous. A child with hypogammaglobulinemia is considered “predictive of risk of infections” (Andersen, 2016, p. 1594). Kendall and Taylor (2016) determined that these types of issues and problems can quickly become a quagmire for the classroom teacher to navigate. They hold that teachers are bound to provide inclusion and support within the regular educational setting for students, unless otherwise noted. So, when a special needs child comes to school without having been given their medication at home, and subsequently engages in behaviors that are disruptive to other students in the class, the teacher has to decide how to communicate this to the administrator and eventually, the caregiver (Garbacz et al., 2015). Then the decision must be made about that child remaining in the least restrictive environment for that class/day (Kurth & Enyart, 2016). Coming across as too lenient diminishes the importance of the class and the medication regimen (McGovern, 2015). Conversely, giving the appearance of a lack of empathy for the struggles of the family with a special-needs child can inhibit future communication (Kendall & Taylor, 2016). The teacher will need to communicate their concerns, but within the confines of respecting the unknown culture at the student’s home (Whyte & Karabon, 2016).

Teachers know that children tend to model their perception of school after their parents (Rege & Almeida, 2013). This perception places the teacher in a somewhat precarious balancing act between acting in the best interest of the child and the best interest of the child’s self-perception in the school setting. Maintaining clear, quality communication with the caregiver can assist the teacher in fostering that positive relationship between educator, caregiver, and student (Kendall & Taylor, 2016).

Caregiver Perspective

Caregivers of immunocompromised children have their own set of needs. These range from organizational to monetary to medical. Besides taking care of their own professional responsibilities, caregivers of immunocompromised children also have an extended home schedule that can run them from early morning to the late evening (Chachia et al., 2016).

Many homes of immunocompromised children have dual-income situations, primarily because of insurance needs and additional costs that attach to raising an immunocompromised child. If not working for multiple incomes, caregivers can still take on increased responsibilities through technological tasks related to the direct care of the child in the home (Spiers et al., 2011). Many times, the technical aspect of care in the home can be beyond the knowledge base of parents. Medical providers sometimes must work with caregivers to help them with roadblocks, such as a lack of resources or understanding complex medical routines (Roesler, 2010). Caregivers need to work in environments where they have the flexibility to attend numerous medical appointments, which can sometimes be at a specialist residing further away. This requires caregivers to be able to stay in contact with multiple stakeholders, including teachers, on a mobile basis. Due to the extended amount of needed care time, caregivers of immunocompromised children may encounter limited personal time or other forms of “escape,” which naturally increases anxiety and stress (Keck & Kupecky, 2014). When combined with a stressful situation of discussing a child’s educational process, it can be very easy for these caregivers to interpret information in a very personal way or perceive a slight where none is intended (Masterson & Brenner, 2016).

Hewitt-Taylor, (2018) determined that by the time the child with special needs has entered school, caregivers have already been told countless times that their child doesn’t have what other children have. They have also probably faced stares from confused patrons at restaurants or stores if their child has a different visage than others. When a teacher or school communicates a critique or concern, the caregiver often perceives that others are underestimating their child, either from an ability or desire perspective (Hewitt-Taylor). These caregivers require information from the school to be presented in the most straightforward and objective manner possible (Pelentsov et al., 2015).

Strickland et al. (2015) determined that although insurance may cover many procedures and supplies that are associated with being immunocompromised, there are still other hidden costs as well. If a hospital trip is required, it is not always possible to bring in outside food due to hospital regulations or limited preparation time. So, although the child will be fed through the hospital, the caregiver(s) who traveled with the child will have to supply their own meals. There are also the increased costs of wear on the vehicles for additional trips, including gas and oil, general maintenance, and having to purchase them more frequently due to increased mileage. If one or more of the caregivers works in an hourly wage profession, they might have to suffer from lost wages if they have already used all of their sick and/or vacation time for prior medical visits (Salvador et al., 2014). All of these can add up over the course of many years, since being immunocompromised is not a condition that is diagnosed in a short period of time, as stated earlier that it takes an average of over twelve years to properly diagnose someone afflicted (Immune Deficiency Foundation, 2007).

A healthy individual who contracts the common flu would only be affected for a couple of days, and might supplement their body's defense system with something like Thera-Flu or NyQuil. An immunocompromised individual might require hospitalization with an IV to supplement the lost fluids and a boost of healthy cells to their immune system. As a preventative measure, most immunocompromised people receive a "new" immune system on a regular basis. This can take the form of an IV or a subcutaneous injection. These treatments can occur once a month to once a week, and can last for one to six hours at a time (Immune Deficiency Foundation, 2018).

One of the major problems with being immunocompromised is that it is not always identified as such right away. Many times, doctors and other health professionals only treat the overlying condition, such as the flu. This results in many people having their eventual diagnosis delayed by several years, sometimes over a decade (Immune Deficiency Foundation, 2018). Because of this misdiagnosis, schools are working with students incorrectly, and implementing plans that are not directly meeting the students' needs, or sometimes even working counter-productively towards them. If a student is eventually diagnosed as being immunocompromised, the schools and staff are usually uninformed or misinformed regarding the best practices and ways to help those students. With the medical maze that eventually leads to a diagnosis of being immunocompromised, caregivers can easily become overwhelmed and confused (Salvador et al., 2015).

Lastly, medical concerns affect the caregivers most of all. According to the Immune Deficiency Foundation (2018) most immunocompromised individuals are not diagnosed correctly when problems first arise, there can be a slew of medical diagnoses that caregivers have to learn about and treat over time. This includes caregivers needing to work with a plethora of medical specialists, as the patient's condition goes through the process of multiple diagnoses. With the limited amount of medical research available for those suffering from being immunocompromised, the Immune Deficiency Foundation shared that caregivers often need to absorb new information that is constantly changing and evolving while they also try and navigate a complex landscape of healthcare. When seeing a specialist, or more than one specialist, time becomes an even more important factor for the caregivers. They can fight their way through delays at medical offices or in the referral process, identification of condition timelines, and the overall quality of care (Jones et al., 2016). Additionally, Pelentsov et al. (2015) have stated that caregivers have the emotional anguish of seeing their child suffer through symptom after symptom, and not know how to fix it. With every specialist visit, there is a raised hope that this visit will provide answers. PI can present itself as a variety of other disorders. One study showed that a Cow's Milk Allergy (CMA) can manifest itself in infants in ways that are similar to being immunocompromised, such as eczema, failure to thrive, and gastrointestinal abnormalities (Melo et al., 2013). All too often, children suffering from being immunocompromised go through a variety of diagnoses, and are finally treated correctly only retrospectively (Keles et al., 2010). Until the "immunocompromised" diagnosis is finally achieved, however, there is the depression that accompanies the end of the visit where the child faces an unknown future and the caregivers experience the frustration and fear that accompanies having a sick child with illnesses that have no obvious cure (Pelentsov, 2015).

Student Perspective

With the growing political pressure of student achievement, students are under more stress than their counterparts of twenty years ago (Weijer-Bergsma et al., 2014). Results of this pressure have shown symptoms such as negative psychological and physical effects (Smyth, 2008). Any time that a person has a chronic medical illness, they run the risk of significant development of any number of psychiatric disorders, including anxiety disorders (Pao & Bosk, 2011). There is a wide-ranging genesis of pressure, originating from parents, teachers, and various news stories throughout the school year. Teachers communicate this pressure through extended work sessions, such as test prep. This can take the form of additional homework or class work that requires students to complete assignments for which they may not yet be prepared (Bryant et al., 2019). Although many of these assignments and assessments are not graded, they are still used to track and rank students. Bryant et al. (2019) also warns that students who are not performing at the same level at their counterparts, this tracking can lead to additional study sessions with support staff away from their classmates. Students that are already feeling different enough in the regular classroom with regards to their ability levels are now feeling even more removed as they might miss a study hall or even a regular class to attend additional work sessions (Immune Deficiency Foundation, 2018). When students are suffering from being immunocompromised, it is nothing less than a life-threatening medical illness. This type of illness qualifies as an emotional trauma and can be a trigger for the onset of PTSD (Post-Traumatic Stress Disorder), according to the DSM-IV definition (Shemesh, 2006).

There is an added physical strain at this level as well. Students not receiving additional study services will usually have a study hall or other time to slow down and let new information received during the day to be absorbed (Smyth, 2008). These students who are being pulled for additional services will not get that needed absorption time. Additionally, Smyth (2008) noted that they are receiving even more new information in their extra study session classes. This extra layering of work can result in physical fatigue, emotional stress, and/or a more negative perspective of the educational experience.

Between the added physical strain and the medical diagnoses, these students are then more likely to be absent more often than their school-age peers. Health studies have proven that rest is one of the most important ways for the body to stay healthy, and heal itself when sick (Wheaton et al., 2016). The increased time in school-related studies means that when students are absent, there is more missed work that needs to be completed. This vicious cycle then is amplified, as students who were already behind in school abilities are now saddled with additional layers of work apart from the "regular" workload of those students not receiving specialized services. This also ties in to the psychological need of the child to feel connected at school (Smyth, 2008). Being absent removes them from friends and, if the teacher is not knowledgeable as to how to best work with their condition, removes an important layer of relating with their teachers/instructors (Wang et al., 2013).

Braund and DeLuca (2018) determined that students also derive motivation from effective communication between the school and home. As the students naturally see and hear their caregivers interact with the school staff, they also develop their own personal cognition of the value of school and education. When students have adults at home who are encouraging of their efforts, they tend to develop with less self-doubt, persevere more readily, and put forth more effort into various school-related tasks (Fan & Williams, 2009). The best way to encourage this positive outlook by the caregivers at home is to have persistent and reliable communication between the school and home. When individuals feel more knowledgeable about something, they are more likely to have a positive perception of it. At the very least, any negative feelings should be negligible at best. In addition to students receiving a positive message about school and education, they are also developing their personal metacognition with regards to education's place within society and the world at large. Wang and Degol (2015) state that these strands of interconnectivity are strengthened and developed over time, and can have far-reaching implications for that student's future personal and professional relationships.

Needs Specific to the Immunocompromised Child

Immunocompromised children are, by definition, individuals who have a greater susceptibility to illnesses (Bousfiha et al., 2018). Therefore, the chances of them missing classes due to illness are much greater than those without this condition. There is no evidence to indicate a strong correlation between students with an immunodeficiency and those students requiring special educational services at school (Redmond et al., 2016), but many of the needs do overlap, either through the provision of an IEP or through the supports of a 504 Service Plan. It is not uncommon for immunocompromised students to leave school early, come late, or miss school altogether for extended medical care (McCabe & Rose, 2015). Additionally, these students will also miss additional days of school due to illness, as their bodies have a natural predisposition for acquiring illnesses, particularly communicable diseases (cold, flu, etc.). These students can easily feel as though they are different from the other students, so being off from school for extended periods of time can affect the students mentally and emotionally, as well as educationally (Smith, 2008).

One of the needs of immunocompromised students is to feel as though they fit in. Students will naturally ask classmates, “Where have you been?” when they are absent for an extended period of time. Eventually, immunocompromised students tend to tire of answering this question, as will almost inevitably occur on a yearly (or more frequent) basis. Vaz et al. (2015) states that having an informational health session with the class, particularly in the elementary level, can be key to addressing the emotional and social needs of the immunocompromised child. This is an opportunity for the school to communicate with the home and ask about the comfort level of the child in addressing it, or even asking the parents to come in and answer questions so the child doesn’t feel as though they are being isolated and put on the spot (Vaz et al., 2015).

When an immunocompromised child has an extended absence, they need a conduit to keep up with the happenings in the classroom. This can be from both an academic and social point of view. Immunocompromised students need access to class notes, organizers, and instructional videos to minimize the gap between themselves and the students who are attending classes on a more regular basis (Able et al., 2015). Additionally, they will need flexible testing time to avoid missing even more classes when they do come back, and possibly even modified or adapted assessments, depending upon the amount of time that they missed (Hardy & Woodcock, 2014). Since the home caregiver will not always be able to pick up work at school before they close, immunocompromised students need a way to shorten the pipeline from school to home, and vice versa, to receive and submit assignments when they are absent.

Summary

The current literature indicates a cohesive viewpoint that information flowing to all educational shareholders increases the likelihood of success for all students. Teachers feel less pressure knowing that they are not the only person responsible for connecting with the child. Parents feel more connected to the school and see more of a partnership. Students feel as though there is a more cohesive message between school and home since all of the parties are sharing the same information.

Schools are required to collect proof of immunization from students' families. However, families can opt out of this if they cite religious or philosophical reasons. The responsibility of the school lies with regard to protecting immunocompromised students and working to ensure that other students are not carrying a potentially life-ending illness. Caregivers face the dilemma of not sending their child to school, which would minimize the risk of exposure. However, they also face the prospect of limiting social contact by the student, therefore potentially damaging their level of peer support (Briggs et al., 2010). Students face the social pressure of having to ask for special conditions (preferential seating, being allowed to wear a mask in class, etc.), and the inevitable social hazing, particularly among teenagers. This was not a prior issue, as immunocompromised students were kept safe with "herd immunity" (Swan, 2015). This meant that the likelihood of contracting a disease was relatively low, since almost everyone was immunized. As the population of those not being immunized increased, so did the potential for immunocompromised students to face one less level of protection (Swan, 2015).

Being immunocompromised is a condition that faces all shareholders involved in the student’s educational process. Everyone not only needs to know their part, but also how their part impacts the others involved. The complexity of the information is as complex as the condition itself.

Chapter Three – Methods and Procedures

Introduction

Immunocompromised students face several obstacles within the school setting. These obstacles also impact the lives of the students' parents/caregivers. Being immunocompromised is a condition that affects the immune system. It prevents the individual's body from effectively fighting diseases that other people can just by taking over-the-counter medicine (Immune Deficiency Foundation, 2018).

The purpose of this qualitative study is to measure the effectiveness of communication between school and home for students diagnosed as immunocompromised. It reviews and discusses the methods that teachers have used, the struggles that students encounter, and the perceptions of parents with regards to both the school and their children's educational access and progress. This chapter will address the methodology used for this study, including the subjects who participated in the study and the settings in which the subjects interact. Additionally, the instruments utilized in the study, the procedure followed for conducting the study, and the data analysis process will be discussed.

Subjects

The participants in this study were parents/caregivers of immunocompromised children. These individuals were contacted due to their direct connection and exposure to the events and parameters involving the child's condition, instead of those individuals who were only familiar with it on a theoretical level or second-hand experience. The consent from each participant was collected through access to a national website dedicated to educating and supporting individuals diagnosed as immunocompromised. After granting consent, an online survey was sent to caregivers. The number of exact caregivers given the survey was determined by the number of responses to the posting on the national board. Fifty-three respondents eventually completed the online survey (Appendix A). These individuals were representative of a range of student ages, from preschool to college. There were six individuals who participated in a personal interview. These were individuals who granted consent for an interview and to be recorded for research purposes.

Setting

This research study was conducted nationwide across the United States of America. Since the initial posting was brought to a national website, then there was the opportunity for individuals from across the country to participate. The website supports families of children with immunosuppressive diseases and parents of school-age children. Only the parents/caregivers were asked to participate and respond to the survey.

Instruments

For this study, respondents shared information through two portals. One was an online survey, which consisted of both Likert scale questions and open-ended questions. The scaled questions allowed for some quantitative information to be utilized in the larger qualitative scale of the study itself. The open responses also allowed for a more in-depth voice for the respondent to fully explain his or her thoughts. The nature of the online survey also allowed for information to be relayed from the respondent to the researcher more quickly, and minimized responses being mislabeled or measured incorrectly when transferring them to a table or chart.

There were eight questions on the survey. The questions themselves focused on areas of education, perception, and personal perspective. Parents/caregivers responded to statements such as, “I feel as though I have access to information that best helps my child.”

The other instrumentation used was a direct interview (Appendix B) used by the researcher with a small sample of the respondents. This helped to ensure the broadest cross-section of the respondent data, and to assist in utilizing the data in such a way that it most accurately reflected the population of impacted people with regards to the condition of being immunocompromised. Interviews also allowed the participants to discuss their responses at length and speak specifically to their experiences supporting their child and working with their school systems. During these interviews, a digital recorder was used to ensure that the respondents’ exact words were being used. A copy of the interview transcript was also sent to the respondents for their review and to ensure accuracy in sharing their findings and responses.

Good research requires good measurement instrumentation. Two of these are reliability and validity (Mohajan, 2017). Since the qualitative data was collected through surveys, and then supplemented through open-ended questions and subsequent in-person interviews, different aspects of perspective were exposed. This allowed for cross-validation and provided triangularization of the collected information. To further analyze the study’s reliability and validity, the survey questions were presented to caregivers who would not be part of the eventual study. Each caregiver was tasked with evaluating the questions and rating them accordingly with a score of 1, 2, or 3. A score of 1 indicated that the question/statement was not one that would provide an actionable response. A score of 2 indicated that the question/statement had potential for actionable response data, but needed to be adjusted in some way. A score of 3 indicated that the question/statement was able to be used for actionable responses as written.

Design of the Study

The purpose of this qualitative study itself is to understand the effectiveness perceived by caregivers of students with an immunocompromised condition. To truly determine this, numbers alone did not give the depth needed to understand the complexity of this subject material. Since there was an interview phase of instrumentation, the qualitative nature of the study is the one that provides the most complete view.

Consideration was given to using a quantitative study, but was ultimately rejected. This was due to the limited nature inherent of such a study. While it would allow for some perspective, it would ultimately inhibit the researcher's ability to inquire follow-up questions that could deal with the respondents' opinions as to more effective methods for communication, or allowing caregivers to give more in-depth emotional responses.

Procedure

The survey's procedure began with compiling a list of various questions that related student learning and caregiver perspective. From this list, questions were grouped by focus area. Questions were then synthesized where the focus was closely linked. This group of questions, then, was presented to the dissertation committee for input. The committee worked with the researcher to adjust the wording of several questions. Then, the questions themselves were tested with a group of twenty-five caregivers. The caregivers were given a link to answer a survey online, and had a week to complete it. Caregivers were chosen to represent a range of student ages. While caregivers were informed as to the reason for the survey, which was to complete a dissertation, the caregivers were not told what the dissertation was studying specifically. After completing the survey, these caregivers provided input that verified that the survey in question was clear, and would provide information directly correlating to the research questions.

To have the survey approved and posted, proof of Immaculata University's Research Ethics Review Board (RERB) had to be submitted, along with a copy of the survey itself. Once it was approved by the RERB (Appendix C) the director himself posted the survey on the national website. The study was posted to a nationally recognized medical area, where individuals can go for primary immunodeficiency-related information. The website was PrimaryImmune.org, and is maintained by the Immune Deficiency Foundation (IDF). The director of the IDF was contacted through both email and phone calls. This national posting cast the widest net possible for caregivers dealing with students who have immunocompromised conditions of one kind or another. Once individuals completed the initial screening process through an online survey, the data was compiled and ranked through several factors. These were used to procure the most accurate representation of the general immunocompromised population. From there, individuals contacted the researcher via email to conduct a one-to-one interview. This allowed for anonymity, as the questions during the interview were medically sensitive. These interviews were primarily open-ended questions that allowed the respondents to go into more depth and detail. Interviews were conducted on the phone after the respondents provided their consent for the interview through the initial contact. The phone calls were recorded and a transcript was provided through the use of an application for mobile devices. All interviewees were aware they were being recorded for research purposes only and consented to the recordings.

Data Analysis

After completion of the surveys, the data was analyzed to determine how many responses agreed or disagreed with the statements in the survey. Responses were compared both across student age level, and parent/caregiver response. When the students' ages were examined more closely, some were found to be either in pre- or post-general education age. These were determined not to be applicable to the study, as these situations were outliers to the intent of the study. The data was used to determine which methods already being used by schools are already effective for communicating with immunocompromised families, and what methods are lacking or are misperceived as being effective. The data was also used to determine how students are affected by proper and improper communication between school and home. Lastly, the data determined how parents' perceptions of school are affected by the different methods of communication, and what their needs as caregivers truly are.

Summary

Due to the nature of their medical conditions, immunocompromised individuals are rarely diagnosed correctly the first time. This inherent lack of correct information and time-lag means that schools will usually be mis- or under-informed about the condition. By the same token, this information can also greatly impact the individuals taking care of an immunocompromised student. A survey was disseminated on a nationwide basis. It only encompassed those caregivers with first-hand knowledge of an immunocompromised child/student. From both the Likert scale survey and subsequent interviews, a qualitative study of the data was summarized. Chapter Four will provide a presentation of the data from the survey and interviews, as well as give possible recommendations to instructional staff, students, and caregivers affected by immunocompromised students.

Chapter Four – Results

Introduction

This study was designed to examine the perceptions of caregivers with regards to communication from and with the school that is attended by their child who has been diagnosed with a primary immunodeficiency disorder. The total number of students referenced in the study is 55. However, that does not match exactly with the number of respondents, as some caregivers have multiple students with primary immunodeficiency symptoms, and others have children not yet of school age. The responses pertaining to these children, then, were not included in the final consideration for this study.

The research conducted in this study includes a summary of responses from parents/caregivers of students with primary immunodeficiency conditions, located throughout the United States. The questions contained within the study focus on two areas within the home-school communication relationship:

1. What factors do caregivers believe impact communication between the school and the home setting of students with compromised immune systems?
2. What tools and procedures can schools implement to ensure effective communication between the school and the home setting of students with compromised immune systems?

The participants in this study, as discussed in Chapter Three, were all parents/caregivers of children/students with primary immunodeficiency medical conditions, and the students who are either currently enrolled in school, or who have recently graduated high school within the last three years. This survey was designed to elicit responses specific to their perceptions regarding how successfully schools communicated with them with regards to their child, and how their child's condition and educational needs were being addressed within the school system. The responses to the surveys, open-ended questions, and interviews were examined to consider and compare the experiences of the various caregivers of students with primary immunodeficiency symptoms.

Caregiver Survey - Demographic Information

The first research question looked at which factors caregivers believed impacted their communication between their child's school and the home setting of their children diagnosed with compromised immune system disorders.

Since the research questions dealt directly with the communication between school and home, it was important to note how much experience the caregivers had with schools and ongoing communication with their child's school. The survey results show the ages of students for which the caregivers are responsible, and therefore can enumerate the level of school experience for the caregivers.

Approximately 3.6% of the students were of preschool age, and were not from the same household. The percentage of students who are of elementary school age (grades Kindergarten through 5th grade) was 21.8% (12 students). Those respondents who had students who would qualify for middle school instruction (grades 6 through 8) numbered 30.9% (16 students) of the survey, and respondents who had students of high school age (grade 9 through 12) came out to 34.5% (18 students) of the participants in the study. The remaining respondents had students ages 19 to 20, and they comprised 9.1% (5 students) of the participants in the survey.

Several factors can impact communication between school and home in both positive and negative manners. Caregiver perception of the school can greatly impact the school and home communication. Caregivers who perceive the school and educational process as a positive experience for their child will be more likely to reach out when there is a problem and work to find a solution. Caregivers with a more negative mindset towards a school will still reach out, although usually to find blame instead of a solution. The same can be said for the school personnel. Teachers who have a positive perception of a caregiver are more likely to reach out to work with them to find solutions for issues within the classroom. Teachers with a more negative viewpoint of the caregiver might not reach out as often, or even at all.

Technology can also impact school and home communication. If a caregiver has limited, or no, access to technology, they might have to rely on letters or phone calls. Letters are not as immediate as emails, and cannot have information embedded in them in the same way. Phone calls are not always able to be returned right away, and can sometimes wind up in a game of “phone tag” for both parties, resulting in delayed information exchange. Conversely, technology has had positive effects on communication, as online gradebooks have made it easier for caregivers to see results more quickly, and for the students to see how impactful various assessments are towards their overall grade. Additionally, email allows for caregivers and teachers to exchange information at hours that are convenient to both. This is especially helpful in the case of caregivers of students with medical conditions, as these caregivers sometimes have unique hours, as discussed in an earlier chapter. Technology has also allowed teachers to attach students work directly to emails, which again builds a stronger relationship between caregiver and teacher.

With regards to the elementary student, managing these positive factors is very important for both caregiver and teacher. Teachers can now provide online portals where students can use conference software (such as Zoom) to watch and listen to the class lessons. This allows students who are missing class for extended periods of time to see and hear the same things that their classmates are experiencing. From an educational perspective, this keeps the gap between students in class and the student(s) missing class small. From an emotional perspective, it helps the student missing class not to be feel “left out” in addition to potentially feeling different for the medical condition alone. While the student might not be able to complete and/or submit all of the work online, it does allow the student missing school an opportunity to engage and keep pace with the rest of the students. The caregivers can also listen in and have a better understanding for the expectations, and help their child respectfully. One concrete example of this would be in mathematics. A popular meme over the last thirty years (or more) has been about the frustration around “new math”. Allowing the caregiver to sit in on the lesson with their child might help the caregiver feel more confident and more comfortable in using these math algorithms with their child at home.

For secondary students, keeping positive communication between school and home shifts more towards the student’s responsibility. However, these students are more technologically savvy, and their teachers can post work that can be done completely online. As these students can also have extracurricular activities and jobs, it becomes even more important for a student missing an extended amount of school to return with as little make-up work as possible. Having a digital folder for students missing class can allow an instructor to post podcasts, lectures, and “how-to” videos. All of these items can allow a student to maintain the more rapid pace of secondary school, and the increased number of instructors in comparison to elementary school.

Caregiver Survey - Communication Perceptions

As shown in Table 4.1, Question 3 queried the quality of communication from school to home with regards to medical concerns. A total of 53 respondents answered this question. Seventeen of them, or 32%, rated the communication as poor. Eighteen respondents, or 34%, rated it as fair. Seven respondents, or 13%, rated the communication as very good. Eleven of the respondents, or 21%, rated the communication as excellent. Thirty-five of the 53 respondents’ answers were skewed towards the two scores indicating the school communication as poor or fair.

Question 4 investigated communication from school to home with regards to academic performance of a child with a compromised immune system. Fifty-three respondents provided information to this question. Six of the respondents, or 11%, rated the communication as poor. Eighteen respondents, or 34%, rated it as fair. Sixteen respondents (30%) rated the communication as very good. Thirteen of the 53 respondents (25%) rated the communication as excellent. For this question, the feedback from the respondents was relatively evenly distributed between the two positive and two negative ratings with regards to communication from the school.

Table 4.1

Questions 3-8: The Caregiver Survey

	Poor		Fair		Very Good		Excellent	
	r	%	r	%	r	%	r	%
3. How would you rate the quality of communication from school to home regarding medical concerns surrounding your child with a compromised immune system?	17	32	18	34	7	13	11	21
4. How would you rate the quality of communication from school to home regarding your child with a compromised immune system overall student performance, specifically with regard to academic scores, strengths, and areas of need?	6	11	18	34	16	30	13	25
5. How would you rate the quality of communication from school to home regarding work missed when your child with a compromised immune system is absent, specifically the material (or concepts) and papers completed in class?	16	30	16	30	12	23	9	17
6. How would you rate the quality of communication from school to home regarding work to be completed when your child with a compromised immune system is absent, specifically with regards to the expectations and timelines for items to be completed and returned to the instructor?	12	23	17	33	12	23	11	21
7. How would you rate the quality of communication from school to home regarding the expected due date of work to be completed when your child with a compromised immune system is absent?	15	29	17	33	11	21	9	17
8. How would you rate the quality of communication from school to home regarding keeping your child with a compromised immune system engaged during absences?	27	54	12	24	6	12	5	10

N = 53
*Note: Not all respondents answered every question

In Question 5, the respondents were asked to rate the quality of communication between school and home when a child with a compromised immune system misses class. The focus here was with regards to materials and papers initially distributed in class. Sixteen of the respondents, or 30%, answered that the communication was poor. An equal number, 16 (30%), answered the communication was fair. Twelve of the respondents or 23%, classified the communication as very good. Nine respondents, or 17%, rated the communication as excellent. The two ratings that classified the school’s communication as poor or fair had approximately 50% more responses than the two ratings classifying the school's communication as very good or excellent.

Question 6 was a related follow-up to Question 5's inquiry regarding absenteeism. Here, the respondents were asked to rate the school's quality of communication regarding the completion of work when a child with a compromised immune system misses school/class. There were 52 responses to this question. Twelve respondents, or 23%, categorized the communication as poor. Seventeen respondents (33%) saw the communication as fair. Twelve of the respondents (23%) rated the communication as very good. Eleven respondents (21%) labeled the communication as excellent. The results here showed more responses (29) for school communication being poor or fair, than in comparison to responses (23) for school communication being very good or excellent.

Question 7 is a continuation based upon the information queried in Question 6. Here, the respondents were asked to evaluate the school's communication with regards to due dates for missed work for a child with a compromised immune system. This question also had 52 respondents. Fifteen respondents, or 29%, saw the communication as poor. Seventeen respondents, or 33%, viewed the communication as fair. Eleven of the respondents (21%) saw the communication as very good. The fewest number of respondents, 9 (17%), rated the communication as excellent. Here, more respondents (32) classified the school communication as fair or poor, while only 20 respondents classified the school communication as very good or excellent.

Question 8 asked about the school's ability to keep a child with a compromised immune system engaged during an absence period. This question had 50 respondents. 27 respondents (54%) labeled the school's communication quality as poor. Twelve more respondents (24%) rated the school as fair. Six respondents, or 12%, saw the school as very good, and 5 respondents, or 10%, saw the school as excellent. Responses classifying the school communication as fair or poor occurred by a three-to-one ratio over the responses classifying the school communication as very good or excellent.

Caregiver Survey - Narrative Questions for Communication Perceptions

Question 3 of the narrative section of the questions asked caregivers to speak to their perceptions of the quality of communication from school to home with regards to their child's medical concerns. As an observation, those who scored schools in the very good or excellent category pointed to a higher frequency of communication as the main reason for the higher rating. These methods of communication ranged from a one-on-one registered nurse to consistent daily emails. One caregiver listed several items, including touchless hand sanitizer, separate bin for the lunch bag, preferred seating when other students are sick, and frequent sanitizing of the classroom. Those caregivers scoring schools as fair or poor also pointed to communication frequency, but on the lower end. One caregiver pointed out that emails from the school nurse are inconsistent at best. Another caregiver stated that the school wants to treat the student "as homebound, which restricts her rights" (Respondent #7) even though there is a 504 plan in place. Yet another caregiver pointed out a lack of communication with regards to "cold and flu outbreaks" (Respondent #12) in the building.

Question 4 inquired as to participants' beliefs regarding the effectiveness of communication with regard to student performance. As in Question 3, the caregivers that rated schools as excellent or very good, did so due primarily to the frequency and transparency of the communication. Caregivers appreciated immediate feedback when things weren’t going well, and also knew they could count on communication at regular intervals. They also appreciated the opportunity for their child to not have to complete all school work if they were absent from school for an extended period of time. Caregivers who rated schools as fair or poor stated they did so due to a lack of consistent and transparent communication. Caregivers also responded very negatively when they believed there was little to no empathy expressed by the school for their child and their medical needs, when it required the child to complete all of the missed school work, regardless of how long they were out of school. As Respondent #4 stated, “While our 504 states he has twice as long to make up work, that isn’t always the case and then we have to fight for it.”

Question 5 asked respondents about work the student needed to complete when he or she missed school, primarily due to any illness directly related to a primary immunocompromised condition. Those caregivers who rated the school as excellent or very good stated they did so for one of two reasons. One reason was that the teacher was able to prioritize work and not hold the student responsible for every item missed while they were out of school. The other primary reason they shared was that the teacher was able to provide notes and/or lectures electronically so the student didn’t feel as though they missed little to no information even though they were at home and not in the classroom. Caregivers rating the school as poor or fair stated they did so primarily because the school/teacher expected all of the information to be completed upon the student’s return to school, or stated that the school communicated little to no information while the student was absent and at home. Participants stated that these situations created a sense of feeling and/or being overwhelmed for both the student and their caregiver.

Question 6 was a continuation of the query in question 5, and asked about the communication with regards to work completion while a student was absent from school due to an absence related to their primary immunodeficiency condition. Caregivers who rated the school as excellent or above average stated that they did so when schools were willing to prioritize the work so only essential work had to be completed. Schools also received high marks when, according to the participants, the teacher's timeline allowed ample time and opportunity for both the student and caregiver to complete items in such a way that did not detract from the student's health recovery. Caregivers who rated their schools as fair or poor did so when there was no perception of empathy for the student and/or the caregiver. In the narratives provided by participants, caregivers shared that schools wanted work to be done while the student was out of school and return all work as completed on their first day back. Caregivers also stated that many schools not expecting work to be done while the student was absent would hand over all of the missed work on them the first day back, particularly with no timeline in place so the students or caregivers could prioritize the work. Caregivers reported feeling as though were not always supported with regards to timelines. Respondent #45 stated, "...the school especially wants the student completely responsible to reach out to each of his 8 teachers and find out what he missed, how to make it up and when to get it completed by...This becomes a horribly overwhelming situation each time my child misses school." Respondent #51 stated, "Sometimes it's overwhelming. We'll be sent home a ton of stuff and not given a date when it's due. We rush to get it done before our child returns to school so we feel they are caught up. We’ve been given projects too and given not much time to complete it.”

Question 7 asked participants to expound upon their responses to question 6, and asked more specifically about the timelines for work completion when a student missed school due to an illness related to the student’s primary immunocompromised condition. As before, those caregivers who rated the school as excellent or very good, shared that they did so due to the transparency of the work and timeline provided. Participants shared that those instructors who demonstrated empathy for their child and their medical condition(s) naturally received more empathy from the caregivers. Respondent #17 stated that, “Teachers have 100 other students, not just my child. I’d like to think the 5 of them have nothing better to do then think about mine, but I’m realistic.” Other participants shared that they believed that the 504 Plan in place for their child also protected them in this area by allowing for additional time or a set number of days based upon the length of the absence. Those caregivers who rated the school as fair or poor stated they did so either due to a lack of communication, or a perceived lack of empathy from the school. Caregivers also believed that there was not an ample amount of time always afforded to their child to complete the needed work from then the student was absent.

Question 8 asked the caregivers to reflect upon how they believed their child was kept engaged while they were absent, due to their primary immunodeficiency condition. Caregivers who rated the school as excellent or above average cited that the use of technology, such as email and Google Classroom, helped their child feel as though they were not missing out on in-class experiences. Those caregivers who rated the school as poor or fair cited a lack of communication as the primary reason for the rating. Many caregivers stated they felt like the school just sent papers home with little to no explanation. Caregivers also shared that it seemed as though their child was being homeschooled, rather than receiving instruction directly from their school or classroom.

After the surveys, subsequent one-on-one interviews were conducted with four respondents to the survey. Their responses showed they perceived communication as the most important factor in evaluating the performance of a school. Interviewee #1 stated that she felt like it, “all falls apart,” when communication is not consistent. The same respondent said that when she, “didn’t know what was going on, where he was, so I couldn’t help.” When asked about their perspective of the importance of communication between school and home, Interviewee #1 stated:

> So open communication is key because who knows their child better than I do? And I can help you [and you] can help me figure out what happened during the day so that's very important. And by doing that, he'll then be more open to learning.

The same interviewee stated that these concerns were why they perceived the cyber school to be much more effective for their child. The caregiver in question is able to sit with her child during the class, and therefore is, “learning as I’m going along with him.” When asked her perception of the school, her response was, “So I'm very happy with the switch. I think it was the best decision I could have made for him.”

Caregivers also shared frustrations with regards to the perceived lack of educated individuals in the schools working with their children. Interviewee #2 stated that she struggled approaching high school for her daughter because she, “was the first kid they ever had like that." Interviewee #1 stated that the second-grade special education teacher was the school librarian the previous year, "So she went through a course during the summer that gave her a certification." She also stated that, "This led to improper physical handling of [her] son when he was having episodes in the school." Interviewee #3 stated that some teachers view students with primary immunodeficiency conditions as, "just trying to get out of school...they're just being lazy." The interviewee stated that this was due to the above-average number of absences that students with PI can accumulate, yet not need to see a doctor due to the nature of their condition.

Caregivers were split into two camps as determined by one primary question: How well do you feel the school tries to speak with, and listen to, you? When caregivers felt that there was even an attempt by the school, then their perception of the school's effectiveness skewed in a positive direction. When caregivers felt as though they were being ignored, or given little to no information regarding their child, then perception scores skewed in a more negative direction. At no point did any caregiver from either of the spectrum state that the communication was not effective. What the caregivers, from all sides, pointed to was how the school's effort made them feel. As Respondent #5 stated in a short answer portion of the survey, "That line of communication is always open [sic] we keep it real and honest." Respondent #27 stated, "The school instantly feels like he should repeat [the grade level] because of his disease and its [sic] not ok with me. Communication is great though." Facing the potential of their child repeating a grade level, this caregiver was still able to compliment the school for having good communication skills.

Research question two asked participants what tools and procedures they believed schools could implement to ensure effective communication between the school and the home setting of students with compromised immune systems? The following information was shared with the researcher through the survey and interviews.

Caregivers reported on a plethora of effective communication mechanisms. These effective communication methods varied with the student's age and school setting. For elementary students, most caregivers reported success with a journal that traveled back and forth with the student. This was sometimes a designated section in a homework planner, or a dedicated journal just for academic and medical information. Some caregivers also reported that they maintained a weekly communication with the school nurse, usually through phone or email. For secondary students, the majority of effective communication was done through the student's guidance counselor or the school nurse. These were usually done through a weekly email, or in some cases, on an as-needed basis.

What caregivers in both categories (elementary and secondary) pointed to as to determine success was the content and frequency of these methods. Elementary caregivers focused more on the medical information in comparison to the academic information. Caregivers reported positively with regards to feeling aware that they understood how and when work surfaces were being cleaned, and if there was a rise in ill students in the building. A modern parallel to this was how many districts published Covid-19 reports on a weekly basis to the general population of students and caregivers. Secondary caregivers also appreciated the medical information, but a slight majority focused more on the academic effects, especially when their child was absent from school for a prolonged period of time. Again, these pieces of information took various forms, and were usually included in the same manner as the elementary and secondary methods mentioned previously.

No evidence was found of a school district proactively publishing this kind of information on their own for general consumption, or even just for the population impacted by immunodeficiency. Again, a modern change to this was the school districts publishing Covid-19 results. None of the respondents mentioned this as something that they would appreciate, but a statement that they connected the two can be made with any kind of certainty.

Summary

The study was completed by linking to a national audience of parents/caregivers who live with someone diagnosed with PI. Questions were presented in a Likert scale design asking the caregivers to evaluate their interactions with the school in several areas that directly impacted their children. The parents/caregivers had children ranging in school-age ranges from K-12. A small percentage of caregivers had children who were of pre-school age, and an approximately equal number had children of college-age (both groups with 3 students), but were able to reflect upon their recent time working with their public school.

The research questions, the literature research in chapter 2, and the data from this limited study support that a poor perception of communication correlates to a poor perception of a school and/or teacher. For all but one of the questions, the majority remained on one side of the positive/negative scale. The Likert scale questions did not provide information that led to a determination of factors that inhibited or promoted communication between school and home. However, the short answer follow-up responses did allow caregivers the opportunity to provide more specific information regarding their communication with their child's school. While several participants did list grievances in this section, no one provided any possible rationale as to what may have led to the concerns with the lack of communication.

In both the initial survey and the subsequent interviews, the respondents' degree of pleasure or displeasure strongly correlated to their perception of the effectiveness of communication they experienced with the school. Chapter Five will discuss the ways in which these findings align or differ from the research findings and considerations for future research in this area.

Chapter Five – Discussion

This chapter presents a summary of the results of the study, the limitations of the study, a discussion of the findings of the research study relative to the literature review findings discussed in Chapter Two, and recommendations for future research.

Summary of the Study

The participants in this study included 53 respondents, all of whom were parents/caregivers of students diagnosed with primary immunocompromised illnesses/diseases, ranging in ages from 2 to 20 years old. All of the participants were from various parts of the United States, as access to the survey was facilitated via a national website.

The Caregiver Survey included questions regarding the demographics of the students, and six Likert-scale questions that inquired about the respondents' beliefs regarding the effectiveness of their schools to the communication with their students. Each Likert-scale question also allowed for the respondent to provide a narrative explaining why the school was doing a good job, or how they could potentially improve their school to home communication.

Following the respondents' completion of their surveys, random respondents volunteered to participate in a brief interview to further elaborate on their answers. These interviews were done via phone and email. The answers provided by the interviews were done to be a representative sample of the total online respondents.

Summary of the Results

Considering the study results, one problem became evident when examining the raw data. When asked if the school was doing an effective job with regards to communication, 54% of the respondents stated that the school was not engaging their students. This is a serious concern, given the previously stated importance of school and home communication. If the perception of school is that poor at home, then there lies the potential of negative talk between caregiver and student of the school itself. This can easily lead to a lack of motivation on both the caregiver's and student's part. While this was not directly apparent in the data itself, it is a reasonable inference that needs to reflected within the interpretation of the results.

Another inference that can be made from the survey responses was that the parents/caregivers noted that consistency of communication is an important procedure to establish and to maintain. This was evidenced through the short answer follow-up responses shared by the participants. Caregivers who stated that they received consistent communication reported an overall higher level of satisfaction with the school.

As every school and classroom is different, so are the needs of students and caregivers. However, there are some similarities that can be determined when looking at the results of the study as a whole. The first research question sought to determine what factors impacted the communication between school and the home setting. Although the specifics differ from person to person, the consensus was that frequency and transparency rated the highest for caregivers. The second question was to determine which tools and procedures could be implemented to ensure this effective communication between school and home.

Caregivers reported on several different methods of communication that provided positive results. Elementary caregivers reported that school-to-home journals were an effective method of sharing information directly between teacher and caregiver. They also reported positive feedback with weekly calls or emails, either from the classroom teacher or school nurse. Caregivers of secondary students reported success with email updates from the guidance counselor or school nurse. However, these were primarily reported as being effective on an as-needed basis. Only a few caregivers reported a need for a weekly update at the secondary level.

The idea that frequency and transparency play the greatest roles in perceived success directly correlates with the literature already produced. As previously stated by Chu (2014), families need meaningful communication with the school. Although 'meaningful' communication does not have a singular number tied to it, there have not been any instances where the words 'meaningful' and 'minimal' were found in the same review. Therefore, it stands to reason that when caregivers consider the word 'meaningful', they expect more than a minimal amount of communication and information. In this study, caregivers reported a more positive perception of the school when they got more information. While Pelentsov et al. (2015) reported that communication also needs to be neutral, or at least free from perceived undue criticism of the student, no caregiver in this study reported both high levels of information and criticism. As a generalization, as caregivers reported higher levels of transparency, they also reported higher levels of satisfaction. The quantity appeared to have a greater impact than the content itself.

Koellner and Jacobs (2014) reported on the effectiveness of multiple forms of assessments for students to better address their individual needs. Within the caregiver responses, ones who reported the highest levels of satisfaction also reported higher levels of options for their child to demonstrate proficiency. This was reported by caregivers to be especially helpful when their child was absent from school for an extended period of time. Caregivers reported a greater appreciation for the teacher and the school when timelines were adjusted or assessment options were given. This appreciation correlates to previously reported research that caregivers see a direct connection between a school's flexibility and perceived care of their child (Higgins & Cherrington, 2017). However, there was not one singular tool or procedure that was reported more than another with any kind of significance, which also correlates to previously published studies (Rafferty et al., 2017).

Combining the results for these two questions would indicate that the answer to the first research question has a much greater impact on caregiver satisfaction than the second question. For the instructor, this can have both positive and negative impacts. The positive aspect of this is that the instructor is not seemingly limited to one or two tools. This gives them a wide berth in which to explore and use what they are most comfortable with on a year-to-year basis. It prevents stagnation, and allows them more professional control over the daily procedures within their own classroom. The negative aspect is that the instructor might have to become fluent in a multitude of tools, and therefore spend a lot more time in one professional development area. This also might hinder the amount of time that it takes to become proficient in one tool if they have to constantly spread their time over learning about a variety of tools. It is important, then, for the school district to work closely with the instructional staff to properly train them in a variety of tools, and provide the proper amount of support to help them use the tools in the most effective way possible (Thessin 2015).

Aside from the mechanics of academic communication, though, is the medical communication component. For caregivers of students with primary immunodeficiency, participants noted that this is what is paramount. From their responses, caregivers wanted to know that the school and staff were aware of their child's condition and were responding appropriately. Rafferty et al. (2017) stated that communication home regarding medical conditions were important to caregivers. The responses from the caregivers in this study reflected that. Caregivers that had high positive perceptions of the school also reported that they received both academic and medical updates from the school. As mentioned previously, these updates were not limited solely to originating from the school medical office. As long as caregivers felt that they were being given the information in a transparent manner, the methodology was not important. A modern parallel to this was how many districts published Covid-19 reports on a weekly basis to the general population of students and caregivers. Secondary caregivers also appreciated the medical information, but a slight majority focused more on the academic effects, especially when their child was absent from school for a prolonged period of time. Again, these pieces of information took various forms, and were usually included in the same manner as the elementary and secondary methods previously discussed.

No evidence was found of a school district proactively publishing this kind of information on their own for general consumption, or even just for the population impacted by immunodeficiency. A modern change to this was the school districts publishing Covid-19 results. None of the respondents mentioned this as something that they would appreciate, but a statement that they connected the two can be made with any kind of certainty.

Limitations of the Study

This research study, by design, was limited in scope examining only the perception of caregivers. These results should not be extrapolated to represent a larger population of caregivers or schools, as estimates of Americans impacted by Primary Immunodeficiency disorders number over 50,000 (Schulman, Ronca & Bucuvalas). Children who were identified as having a diagnosis of being immunocompromised, and educators who identified themselves as instructing immunocompromised children were considered, but were ultimately excluded due to the overwhelming amount of data that would have been collected between all three groups.

As a both a parent of a child diagnosed with a medical condition and as a teacher, this author's experiences impacted the reasoning and questions contained within this study. Knowing that this bias could have been impactful, this author worked hard with the dissertation committee to be sure that the language used on the survey and interview were as neutral as possible and that the survey and interview questions did not lead the participants towards any pre-considered conclusions or results. Many of the respondents were both caregivers of immunocompromised children and also teachers. These dual roles could have impacted their impressions of the positive or negative experiences with their children's schools.

Relationship to Other Research

Chapter Two discussed the current literature findings regarding communication between school and home for student's with compromised immune systems and/or significant medical needs within the educational environment. Many of the findings in Chapter Two were reinforced by the findings from this study.

The commonality amongst the cases was communication (Higgins & Cherrington, 2017). Even when things weren't done perfectly, from either side, having an open and consistent dialogue provided a much more positive experience for everyone involved (Seki et al.,2016). When communication was not forthcoming, the level of negativity was raised, and threats on either side seemed to materialize. Schools threatened to hold a child back because they didn't understand how the child's condition lent itself naturally to missing multiple educational days, and the schools had an attendance policy in place that prevented a child from moving to the next grade if they passed the threshold number of missed days (Johnson et al., 2015). Caregivers threatened to report a building administrator to the superintendent or hire a lawyer. Both sides eventually managed to ebb back to a more neutral position, but only after fully communicating. These situations were more than likely avoidable if one or both parties had taken the time at the outset to fully understand and be appreciative of what was expected and reasonable (Seki et al., 2016).

The narrative responses that were conveyed through the surveys and interviews were stories that this researcher heard a number of times throughout the process of conducting this study. Given the greater ease of online record access to medical information and communication currently, in comparison to ten or twenty years ago, it was noted many times that caregivers still felt frustrated when trying to work with some of their children's schools.

Caregivers noted that schools might not be acutely aware of all the medical concerns regarding their child. However, participants noted that schools/teachers just making the attempt at consistent and transparent information sharing would go a long way in making the caregiver feel as though the school has empathy for what they and their child are experiencing. If a school was willing to have a conduit of communication that was consistent and transparent, then the caregiver was equally willing to increase their level of trust and understanding with that school.

Research conducted by Seki et al. (2016) indicated that more effective communication between school and home is built by increased transparency from the school. As indicated by caregivers rating schools as excellent or above average, consistent and transparent communication was listed as a major factor as to why the school was ranked highly. Conversely, a lack of communication was used as a rationale by caregivers to rank a school as fair or poor.

An increase in parental confidence in communication with the teacher and an increase in the positive perception of a child’s educational experience (Higgins & Cherrington, 2017) have been directly related to caregivers receiving multiple pieces of information regarding their child. As demonstrated in Question 4 from the survey, the narratives provided by the respondents showed that having a higher quantity of information directly correlated to a caregiver ranking a school as excellent or above average. Conversely, those caregivers who received, what they felt, as less than adequate amounts of information rated the schools as fair or poor.

Herold (2018) posits that caregivers look at a school more favorably when information is sent directly to caregivers, rather than the school sharing information passively by having the caregiver access information on the school website or social media account. As shared by caregivers in the narratives of this study, they rated schools as fair or poor when they feel that the school did not reach out and let them know about an uptick in the number of cold or flu cases within the school, or when the school nurse did not proactively reach out. As a matter of comparison, caregivers who had constant, proactive communication from the school rated the school as excellent or above average. One caregiver noted that the school secretary was the access point for both themselves and their student. Caregivers also reported a more favorable view of the school when they received information before they even knew to ask for it.

In summary, Dotger (2019) cautioned that an individual's knowledge is a confluence of their personal experiences. As the caregivers have shown through both survey and narrative responses, their personal experiences have greatly colored their view of the effectiveness of their child's school (for supporting them when their medical needs intersect with their academic needs). Educators must be more aware of this, and ensure that their communication home, especially to caregivers of children with medical/special needs, is consistent and transparent.

Recommendations for Future Research

The data from the survey and narratives indicated that a potential for follow-up research would be to investigate how to use the information received from the school to help engage the child with a compromised immune system at home. Are there items for engagement that are specific to the child with a compromised immune system, or is the idea of engagement at home a perceived issue for children of all backgrounds and situations?

Considerations for future research could also include gathering perceptions of students with primary immunodeficiency conditions. Do they share the same perceptions as their caregivers? Is there a change in viewpoint between various age groups? With the advancement of technology education, there is a potential for higher levels of student independence, and therefore less reliance on information directly from the educator or the action of the parent as an intermediary (in older students). As schools, particularly at the secondary level, transition to providing more online educational opportunities, do students with primary immunodeficiency symptoms see a potential for fewer needed accommodations?

Another realm for potential research would be gathering perceptions of educators working with students who have primary immunodeficiency symptoms. What do they feel has been successful so far? Do they feel as though they have had adequate training and resources to effectively assist students and caregivers? What information might they believe is missing to better support their medically involved students remain up to date with their academic work and expectations? Is there a discrepancy between perceptions of elementary educators and those working at the secondary level?

In addition to gathering perspectives from students and educators, study could be done to examine how schools are currently handling situations involving students with adverse medical conditions. In light of the research gathered for this study, it appears that many schools deal with medical issues in a reactive way, rather than a proactive way. Are there things that schools can do to work with students and families before major problems arise? Fifty-four percent of the respondents in this study stated that they were experiencing communication problems between school and home. If this is representative of a majority of schools, can there be a mechanism implemented by schools to greatly reduce this number? Given the rise in school-to-home communication as a result of the recent pandemic, it stands to reason that the tools available to schools have greatly increased in number and effectiveness and that these tools will continue to exist and be utilized as schools move forward, post-pandemic.

With these new tools, another area of future research would be the creation of a toolkit for schools that would compile accessible skills and techniques to directly address students who are absent for extended periods of time due to medical concerns. This study could also include a discussion regarding the identification of a specific point- person for that parent to contact (social worker/counselor/nurse, depending upon school and staffing) who might become the person to help navigate the system and organize missing assignments, consider flexibility of assignments, assist with differentiation of instruction (if possible) and help to maintain consistency between the school and home.

Conclusion

The overarching outcome from this study indicated that there is a need for communication that is consistent and transparent between school and home. When caregivers believed they were being given as complete a picture as possible, then their perceptions of the school increased significantly. This information covered multiple areas, including academic progress, timelines for work missed during class, and medical conditions at the school. At no point in the research did any caregiver really critique the quality of the information once they received it, but rather the initial lack of communication sparked a lower rating.

Parents/Caregivers of students with primary immunodeficiency illnesses want to know that their child, like all children, is being cared for in the best way possible. These individuals are accustomed to receiving a plethora of medical information. As a generalization, then, they might expect the same delivery of educational information from their child’s respective schools or teachers. Being aware of this mindset can help educational institutions when communicating with parents/caregivers of students with primary immunodeficiency symptoms. If effective communication can help even one more parent and prevent or decrease academic loss, then it is something to which every school and caregiver should aspire. This is the potential power of consistent and transparent communication.

Caregivers stated that they have a higher perception of schools when they feel as though they have been heard and receive empathy. The following quote from Fred Rogers explains the importance of trust and open communication between home and school when supporting students who are immunocompromised:

> Anything that’s human is mentionable, and anything that is mentionable can be more manageable. When we can talk about our feelings, they become less overwhelming, less upsetting, and less scary. The people we trust with that important talk can help us know that we are not alone (Rogers, 2013).

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Appendix A – Survey Questions

Research Study

Parent/Guardian Perceptions of School to Home Communication for the Immunocompromised Student

We are currently engaged in a study of school to home communication surrounding children with compromised immune systems. You have been invited to participate in this study because you are a parent/guardian of a child with a compromised immune system. To help us gain further insights into this area, you will be asked to complete a brief online survey that should only take approximately 10 minutes. In addition, you may be contacted to request a short telephone or in-person interview consisting of three additional questions related to the school to home communication for the immunocompromised student.

Upon completion of this study's data analysis a formal report detailing the research and findings will be available.

The data you provide will be recorded anonymously, and your participation and anything you say during the interview will be held in the strictest confidence. Any notes taken during the interview will not include your name.

We welcome any questions about the study at any time. Your participation in this study is voluntary and you may refuse to participate at any time without consequence or prejudice. Any questions about this study can be directed to me, Marsha L. Fabian-Griffith, doctoral student candidate in the Education Division at Immaculata University. I can be reached at (717) 201-8580. You may also contact Jeanne Dagna, Ed. D. in the education division of Immaculata University at (610) 547-9943 or at jdgagna@immaculata.edu.

Any questions about your rights as a research subject may be directed to Dr. Thomas F. O'Brien at (610) 647-4400 x3284 or at tobrien@immaculata.edu. Dr. O'Brien's office is located in room 1 of Loyola Hall.

Please “check” the appropriate selection below to indicate whether you give consent to participate in this voluntary study. Please note that giving consent to participate in this study will not waive any of your legal rights.

☐ I hereby voluntarily agree to participate in this study with the understanding that every effort will made to ensure the confidentiality of my responses to this survey to the degree permitted by the technology used.

☐ I do not agree and choose not to participate in this study. (Please exit this survey by clicking on the “Exit this survey” button located on the bottom corner of this page.

How old is your child? _______________

1. How would you rate the quality of communication from school to home regarding medical concerns surrounding your child with a compromised immune system?

☐ Excellent ☐Very Good ☐Fair ☐Poor

a. What are some strategies already being implemented that you feel are successful?

b. What are some strategies already being implemented that you feel could be improved?

2. How would you rate the quality of communication from school to home regarding your child with a compromised immune system overall student performance?

☐ Excellent ☐Very Good ☐Fair ☐Poor

a. What are some strategies already being implemented that you feel are successful?

b. What are some strategies already being implemented that you feel could be improved?

3. How would you rate the quality of communication from school to home regarding work missed when your child with a compromised immune system is absent?

☐ Excellent ☐Very Good ☐Fair ☐Poor

a. What are some strategies already being implemented that you feel are successful?

b. What are some strategies already being implemented that you feel could be improved?

4. How would you rate the quality of communication from school to home regarding work to be completed when your child with a compromised immune system is absent?

☐ Excellent ☐Very Good ☐Fair ☐Poor

a. What are some strategies already being implemented that you feel are successful?

b. What are some strategies already being implemented that you feel could be improved?

5. How would you rate the quality of communication from school to home regarding the expected due date of work to be completed when your child with a compromised immune system is absent?

☐ Excellent ☐Very Good ☐Fair ☐Poor

a. What are some strategies already being implemented that you feel are successful?

b. What are some strategies already being implemented that you feel could be improved?

6. How would you rate the quality of communication from school to home regarding keeping your child with a compromised immune system engaged during absences?

☐ Excellent ☐Very Good ☐Fair ☐Poor

a. What are some strategies already being implemented that you feel are successful?

b. What are some strategies already being implemented that you feel could be improved?

Thank you for taking time to complete this survey.

As a part of the regular process of collecting accurate data, the researcher may contact you requesting a telephone or in-person interview directly related to this study. Your participation in this interview is completely optional.

If you would like to participate in this brief optional interview, please contact Marsha L. Fabian-Griffith at (717) 201-8580 or by email at mfabian1@immaculata.edu.

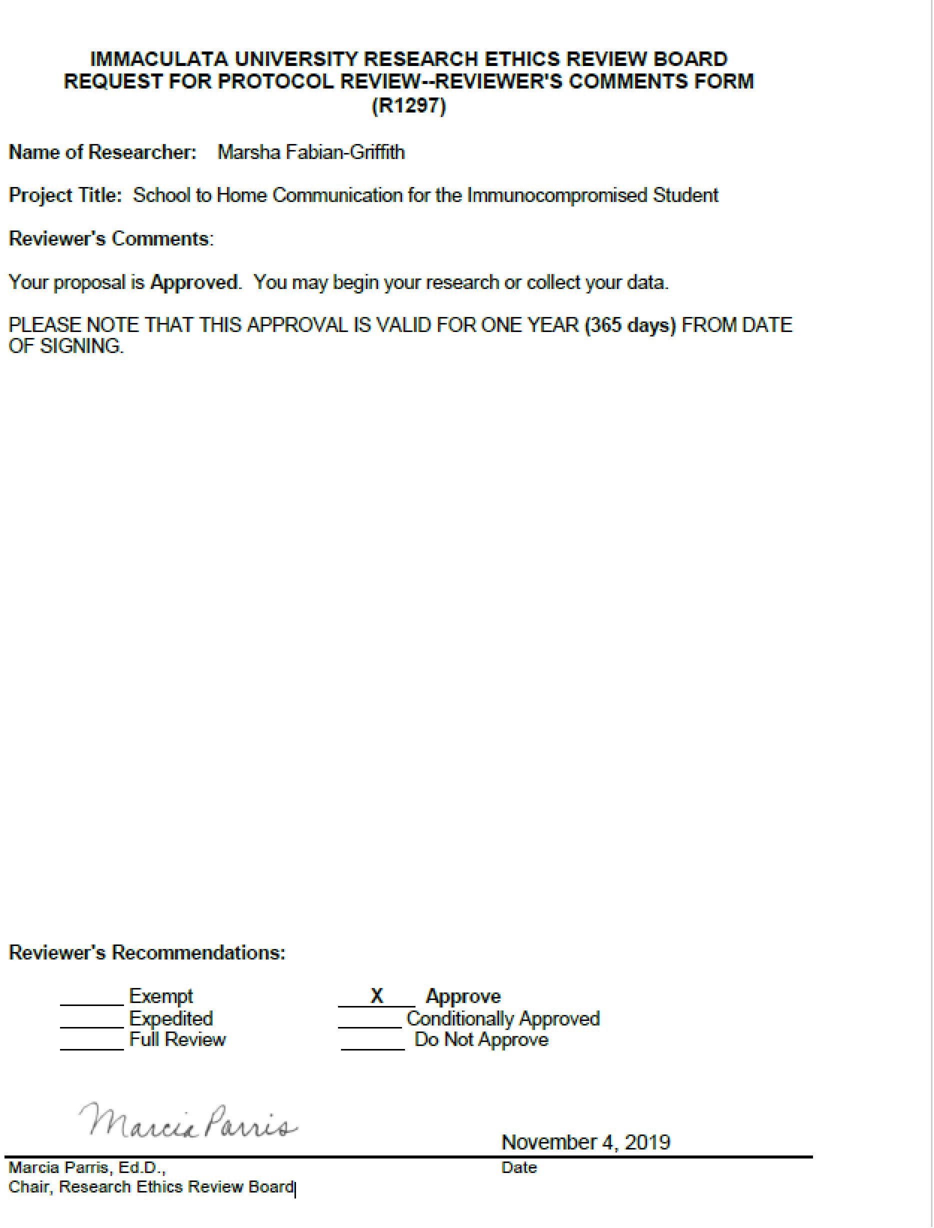
Appendix B – Interview Questions

1. What are some school to home communication strategies that have already been implemented that you feel are successful?

2. What are some school to home communication strategies that have already been implemented that you feel could be improved?

3. Do you have any other comments or information that you would like to share concerning school to home communication for the immunocompromised student?

Appendix C – RERB Approval Page



IMMACULATA UNIVERSITY RESEARCH ETHICS REVIEW BOARD
REQUEST FOR PROTOCOL REVIEW--REVIEWER'S COMMENTS FORM
(R1297)

Name of Researcher: Marsha Fabian-Griffith

Project Title: School to Home Communication for the Immunocompromised Student

Reviewer's Comments:

Your proposal is **Approved**. You may begin your research or collect your data.

PLEASE NOTE THAT THIS APPROVAL IS VALID FOR ONE YEAR **(365 days)** FROM DATE OF SIGNING.

Reviewer's Recommendations:

______ Exempt
______ Expedited
______ Full Review

__**X**__ **Approve**
______ Conditionally Approved
______ Do Not Approve

Marcia Parris

Marcia Parris, Ed.D.,
Chair, Research Ethics Review Board

November 4, 2019
Date