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School Nurses' Experience of Barriers to Care in Children with Type 1 Diabetes

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ABSTRACT

SCHOOL NURSES' EXPERIENCE OF BARRIERS TO CARE IN CHILDREN WITH TYPE 1 DIABETES

Purpose: The purpose of the study was to gather data on the lived-experience of providing and coordinating type 1 diabetes care in the school setting from school nurses who practice in California. **Methodology:** A descriptive phenomenological qualitative study design was used to collect data through structured interviews with 13 school nurses. Descriptive coding was used to analyze the interview data. **Findings:** School nurses face multiple barriers to care when providing type 1 diabetes care in the school setting. The three major themes school nurses encountered were difficulty with care coordination, communication, and parents.

Eden Donahue
April 2018

SCHOOL NURSES' EXPERIENCE OF BARRIERS TO CARE IN
CHILDREN WITH TYPE 1 DIABETES

by

Eden Joseph Donahue

A project

submitted in partial

fulfillment of the requirements for the degree of

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APPROVED

For the California State University, Northern Consortium
Doctor of Nursing Practice:

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CHAPTER 1: INTRODUCTION

School nurses are at the forefront of providing safe, adequate healthcare to children in the school setting. The National Association of School Nurses [NASN (2017)] defines school nurses as “the leaders who bridge health care and education, provide care coordination, advocate for quality student-centered care, and collaborate to design systems that allow individuals and communities to develop their full potential.”

School nurses are responsible for coordinating care for children with complex medical issues while facing an ever-increasing school nurse to student ratio. One such complex medical issue is how to provide care to children with type 1 diabetes (T1D) in the school setting with recent legislative changes that allow for unlicensed assistive personnel (UAP) to provide T1D care. Little is known about the challenges school nurses encounter when trying to provide care to children with T1D in the school setting. This study explored the barriers school nurses face when trying to provide T1D care in the school setting with limited school nursing resources.

Significance of School Nurses Providing Care for Children with Type 1 Diabetes

Defined as one of the most common chronic diseases [Centers for Disease Control and Prevention (CDC), 2014], T1D affects 0.25% of children under 20 years of age in the United States. Treatment includes hospitalizations, frequent office visits to specialists, multiple daily blood glucose (BG) checks, insulin administration, carbohydrate counting, and dietary modifications. The steady rise of children with T1D also affects school nurses in California. School nurses are tasked with the responsibility of care coordination, direct or indirect T1D care,

supervision of trained personnel, and limited resources when providing care to children with T1D. By using the chronic care model, the researcher looked at the challenges faced by school nurses related to providing care to children with T1D in order to create a holistic healthcare experience and advocate for better, consistent healthcare access across healthcare settings (Wagner, 1998).

The researcher utilized the chronic care model to design and implement the project (Wagner, 1998). The chronic care model focuses on the importance of the interaction between informed, motivated patients and families, and knowledgeable providers, such as school nurses (Wagner, 1998). The chronic care model is a community health based model and it was important for the researcher to utilize a model that reflected the community based nature of school nursing. School nurses are the conduit between the community, health systems, and patients in order for improved health outcomes for children in the school setting.

Problem Statement

School nurses are faced with higher school nurse to student ratios, more children with complex medical needs, and difficulty coordinating care. The most recent data from 2015 showed that the school nurse to student ratio in California was one to 2,784 (Lucile Packard Foundation for Children's Health, 2017). The Healthy People 2020 objective suggests a school nurse to student ratio of one to 750 [Office of Disease Prevention and Health Promotion (ODPHP), 2017]. The American Academy of Pediatrics (AAP) Council on School Health (2016) recommends having a school nurse on every school site. Currently, California does not meet the AAP (2016) recommendation and has three times the school nurse to student ratio as recommended by Healthy People 2020 (ODPHP, 2017).

School nurses are also trying to manage rising rates of children with chronic illness, especially T1D. The CDC (2014) categorizes T1D as one of the most common chronic diseases among children. From 2001 to 2009, Dabelea et al. (2014) found a 21.1% increase in the prevalence of T1D among youth in the United States. School nurses must provide safe, effective care in the school setting to an increasing population of children with T1D with limited resources.

School nurses in California practice in a variety of settings, including rural, suburban, and urban settings. Families and children who live in rural settings or farther away from large healthcare systems face difficulties with access to healthcare services. Van Arsdale and Barry (2008) found that 197 residents in a rural community reported the need to access healthcare for their children. Of those 197 residents, 14.2% of residents were unable to obtain the needed healthcare resources for their children due to poverty and the requirement to access out of the area specialty healthcare services (Van Arsdale & Barry, 2008).

With the increase of children with T1D, recent legislative changes, and the complexity of T1D care, school nurses in California must decide how to handle the issue of direct care to children with T1D in the school setting. It is not clear how recent legislative changes, limited resources, and lack of local specialty healthcare services have affected school nurses in California and the care they provide to children with T1D in the school setting.

Purpose of the Project

The purpose of this phenomenological qualitative research study was to analyze the barriers that school nurse's encounter when providing care to children with T1D in the school setting. With recent legislative changes, school nurses in California are tasked with either: a) providing direct, one-on-one care to students

with T1D, b) training registered nurses (RNs) or licensed vocational nurses (LVNs) to provide direct care to students with T1D, or c) training UAPs to provide direct care to students with T1D [American Diabetes Association (ADA), 2016]. This study was an assessment of the unique characteristics of care coordination for school nurses in California who provide care to children who travel 50 miles or more to access T1D specialty healthcare.

CHAPTER 2: LITERATURE REVIEW

School nurses are responsible for coordinating T1D care for children by communicating with the parents, child, specialty healthcare providers, and school personnel to create a diabetes medical management plan (DMMP). School nurses can encounter difficulty when communicating with each party to ensure a continuous plan of care for a child with T1D. School nurses must ensure communication of T1D information across the parents, healthcare providers, and school personnel.

School nurses are also responsible for counseling parents during and after the diagnosis of T1D in their child. Due to the severity of hypoglycemic and hyperglycemic symptoms in children with T1D, parents can develop fear around low or high blood sugar levels (BSL). High BSLs generally result in long-term negative health effects whereas low BSLs can cause immediate death. In the researcher's previous experience as a school nurse, many parents of children with T1D expressed overwhelming fear of their child experiencing hypoglycemia when compared to hyperglycemia. The following section will discuss various research studies related to school nurses and intricacies of T1D care.

Parent Response to Type 1 Diabetes

An article by Freckleton, Sharpe, and Mullan (2014) analyzed the effect of maternal fear of hypoglycemia on their children's BSL. Freckleton et al. (2014) found children with T1D had a significantly higher frequency of high BSLs when their mothers were afraid of hypoglycemic episodes ($F(7, 60) = 2.97, p = 0.010$). In addition, Freckleton et al. (2014) found that children with T1D had high-risk BSL when their mothers were afraid of hypoglycemic episodes ($F(7, 60) = 3.22, p = 0.006$). It is unknown if the parent altered the child's diet, insulin regime, or

other factors to decrease the chance of a low BSL that accounted for the high BSL levels of the participants (Freckleton et al., 2014).

Jönsson, Lundqvist, Tiberg, and Hallström (2015) designed a study to analyze children newly diagnosed with T1D ($n = 69$) and their parents' health-related quality of life (HRQOL). Jönsson et al. (2015) used the following data collection instruments: a) PedsQL™ Family Impact Module, b) PedsQL™ 3.0 Diabetes Module Scale, and c) PedsQL™ Health Care Satisfaction Generic Module. These instruments have been proven reliable and valid when used to measure HRQOL for children with chronic conditions and their families (Varni, Sherman, Burwinkle, Dickinson, Dixon, 2004). Each data collection instrument analyzed five to six scales of HRQOL in the children and families using questionnaires with Likert scales.

Data was collected from the child with T1D and parent at the time of T1D diagnosis and one year after diagnosis. Statistical significance was set at $p < 0.05$ for independent t-test, paired t-test, and one-way analysis of variance (ANOVA). Mothers had a lower HRQOL than fathers at time of diagnosis ($p = 0.003$) and 1 year after ($p = 0.041$). Parents of children ages 5 to 7 worried more than parents of older children ($p = 0.037$). A weakness was that the siblings of the child diagnosed with T1D were not involved in the study. Jönsson et al. (2015) analyzed the experiences of the mother, father, and child at the time of T1D diagnosis and one year after diagnosis, which was a study strength.

Lowes et al. (2015) studied the lived experiences of the children and their families related to living with and managing T1D while receiving T1D care through a qualitative descriptive analysis. Children with T1D between four and 15 years of age and their parents were recruited from 26 pediatric diabetes clinics ($n = 693$). Age appropriate questionnaires were completed for a baseline and one year

later; free text comments were transcribed and entered into a database. The researchers analyzed and catalogued related patterns. The researchers discovered the following themes: a) parental anxiety when communicating with HCPs, b) increased stress when attending appointments, c) multiple emotional responses to T1D, and d) the need for emotional support during appointments. A limitation was that children and families who had strong positive or negative feelings were more likely to complete the questionnaires. A strength was the large sample size (n = 693) across a variety of settings.

School Nurse Response to Type 1 Diabetes

Marshall, Gidman, and Callery (2013) conducted a qualitative study with nurses in the United Kingdom. Marshall et al. (2013) discovered the following themes related to nurses and T1D care: a) uncertainty regarding the policy and/or legal background, b) difficulty communicating with school personnel, c) difficulty communicating with parents of children with T1D, d) T1D knowledge was gained through experience, and e) uncertainty about what best practice meant for T1D care in the school setting.

Marshall et al. (2013) found that nurses felt uncertain about how to provide T1D care in the school setting due to ambiguous policies related to providing health care in the school setting. Nurses cited policies that advocate for a child's right to attend school but there was uncertainty related to how to carry out those tasks. There were also questions related to who was responsible for initiating and coordinating care for children in the school setting. Another theme that Marshall et al. (2013) discovered was that nurses were uncertain about what best practice meant for T1D care in the school setting. Nurses reported a wide variance of

supervision levels, time spent with children with T1D, and training regime frequency for school personnel.

Wang and Volker (2012) conducted a qualitative study with school nurses who provided T1D to children in Taiwan. Wang and Volker (2012) found similar themes as Marshall et al. (2013) but the study by Wang and Volker (2012) stressed the importance of interdisciplinary teamwork and school nurse specific issues. Wang and Volker (2012) discovered the following themes: a) importance of empathy when communicating with parents and children, b) need for more T1D knowledge and experience, c) importance of care coordination, and d) difficulty providing T1D care in the school setting versus a hospital setting.

Literature Gaps

A majority of the research articles that address school nurses and their experience with providing care to children with T1D are over five years old. Another limitation identified was that a majority of the research articles that specifically addressed nurses and how to provide T1D in the school setting were conducted outside of the United States. The researcher proposed a study that would assess the barriers that school nurses in California experience when trying to provide and coordinate care for children with T1D. The researcher also assessed the unique characteristics of care coordination for children with T1D who access out of the area specialty diabetes care.

The stressors discussed above highlight the need for additional research of the barriers encountered by school nurses. The parent's fear of low or high BSL's and the school nurse's stressors of providing T1D care can negatively affect the care coordination necessary to provide adequate T1D care in the school setting. School nurses who provide care coordination for children with T1D face a

multitude of stressors; these stressors are exacerbated when school nurse to student ratios are high and when there is a lack of communication between the families, specialty care providers, and school nurses.

CHAPTER 3: METHODOLOGY

Study Design and Research Question

As the project focused on the lived experience of school nurses, a qualitative research design was essential to capture the unique characteristics of school nursing. The following research question guided the project: how do school nurses perceive the barriers to providing care to children with T1D in the school setting? The qualitative design that best fit the research question was a descriptive phenomenological qualitative study (Powers, 2015). An important characteristic of the descriptive phenomenological study design was the focus on the importance of the lived experience. It would be difficult to analyze the barriers to care that school nurses faces without gathering data on the lived experiences through their own description of the barriers.

Population and Setting

The population focus was a group of students who were enrolled in a school nurse credential program in California. The researcher recruited participants through the school nurse credential program in California. The population sample had the following similar characteristics: a) have a preliminary or clear school nurse credential, b) live in California, c) provide direct or indirect care of a child with T1D in the school setting who access out of the area specialty T1D care, d) out of the area was defined as the child with T1D having to travel over 50 miles to access specialty T1D care, and e) be over 18 years of age. Approximately 150 students could have met the research criteria. The researcher gathered qualitative data from 13 school nurses who provided care to children with T1D.

The researcher recruited participants through emails, which highlighted an opt-in study focused on the lived experience of school nurses providing T1D to children in the school setting. The researcher utilized a purposive sample for the study. The school nurse credential program coordinator distributed the recruitment email to students in the school nurse credential program. A \$10 Amazon gift card was used as an incentive to enhance participation.

Data Collection

In order to analyze the barriers to care, the researcher gathered input from the school nurses. Using structured interviews, the school nurses provided a unique perspective of providing T1D care in the school setting as well as the barriers to providing T1D care in school setting. The recruitment of school nurses who provided care for children with T1D occurred through outreach to a California school nurse credential program. Participants opted-in to the study through Survey Monkey. The use of open-ended interview questions allowed the school nurses to voice their unique perspective in their own words (Saldaña, 2011). The researcher developed the interview questions in order to reflect the unique characteristics of school nurse practice in California. (Appendix A)

As there are only four school nurse credential programs in California and the researcher teaches in one of the programs, a research assistant was utilized to reduce the potential conflict of interest. A research assistant conducted the initial outreach, interviews, and follow-up with guidance from the researcher. The structured interviews took approximately 30 minutes to allow for thorough feedback and insight from the school nurses. The interview process took place via telephone to enhance the quality of data collected and provided school nurses the opportunity to describe the barriers to care in their own words. The interviews

were recorded with the participants' permission with a digital recorder and transcribed by the researcher and research assistant. With the information from the school nurses, the researcher analyzed the results to gain a comprehensive understanding of the barriers to care for school nurses who provide care to children with T1D.

Data Analysis

The phenomenological design of the study required multiple levels of analysis (Hays & Singh, 2011; Powers, 2015). Demographic data was collected from the participants to ensure variance between practice settings. The researcher first established credibility by verifying that the transcribed interview data was correct by comparing it to the original audio recordings. During the interviews and the first reading of interview transcripts, an overarching perspective of the qualitative data was obtained (Hays & Singh, 2011; Powers, 2015). The researcher was immersed in the data for five months. During that time, the researcher kept a field journal to keep notes on the broad perspectives, codes, and themes.

Credibility and Rigor

Once the researcher had a broad perspective of the content, themes and codes began to emerge and trends were identified. The researcher then reflected on these themes (Hays & Singh, 2011; Powers, 2015). The process of coding and reflecting happened continually throughout the analysis phase of the project. The researcher utilized descriptive coding; the researcher then clustered and categorized codes, which identified themes and sub-themes. The researcher identified patterns throughout the review of the recordings and transcripts.

Two coders were used to further establish credibility and rigor. The researcher coded the interview data three times, which resulted in three themes and 12 subthemes. The researcher was the primary coder and the project chair was the secondary coder. After coding the data, the researcher and project chair compared, discussed, and agreed upon the themes and sub-themes to establish consistency. With guidance from the project chair, the researcher analyzed the interview results and identified common themes related to the barriers of care, which are discussed in the following chapter. The researcher assistant also verified the themes and sub-themes with the participants; six participants agreed with the themes and sub-themes.

Trustworthiness

In order to establish trustworthiness, the participants were aware of the researcher's goal for the study. The participants knew the goal of the research study was focused on the barriers of care. The participants were also aware of the researcher's background as a school nurse and the researcher's involvement in a school nurse credential program to enhance trustworthiness. The participants were able to opt-out of the study at any time. The resulting themes and sub-themes will be discussed in the next section.

CHAPTER 4: RESULTS

The researcher began the study through the collection of demographic data, which provided information about the setting, characteristics, and background of the participant (see Table 1, Table 2, and Figure 1). The demographic information ensured a variance between practice settings among the participants. The researcher then analyzed the interview data using the descriptive phenomenological methods described in the above section. Through the data analysis, the researcher discovered three themes and 12 sub-themes (see Table 3).

Demographic Data

The researcher collected demographic data from all 13 participants. The participants were at the beginning of their school nurse career; the participants had been a school nurse for an average of 4.46 years (see Table 1). Although the researcher focused on school nurses, it was important to assess how long the participants had been a registered nurse; participants had an average of 13.62 years of registered nurse experience (see Table 1).

The researcher felt it was important to assess the participant's school nurse to student ratio. On average, the participants were responsible for caring for 2804.62 students (see Table 1). The school nurse to student ratio in the Lucile Packard Foundation for Children's Health (2017) was similar to the school nurse to student ratio in this study; in contrast, the school nurse to student ratio in this study is three times larger than the school to student ratio proposed by the Healthy People 2020 objective (ODPHP, 2017). The researcher also asked the participants how many children with T1D were on their caseload; the average number of children with T1D on each participant's caseload was 5.62 (see Table 1).

Table 1

School Nurse Demographic Information

School Nurse Information	Mean (n = 13)
Age	44.08
Years as a school nurse	4.46
Years as a registered nurse	13.62
School district population	22,484.62
School nurse ratio	2804.62
Children with type 1 diabetes	5.62

Another important characteristic of the participants was the region of California and the setting of each participant's school nurse practice. There was even distribution between northern, central, and southern California participants (see Table 2). There was also even distribution between rural, suburban, and urban practice settings (see Table 2).

Table 2

School Nurse Practice Setting – Region and Setting

Setting	Participants
Northern California	6
Central California	4
Southern California	3
Total	13
Rural	4
Suburban	6
Urban	3
Total	13

The researcher also assessed the ethnic make-up of the participants. There was a range of ethnicities reflected in the participants although a majority of the participants identified as White or Caucasian (see Figure 1).

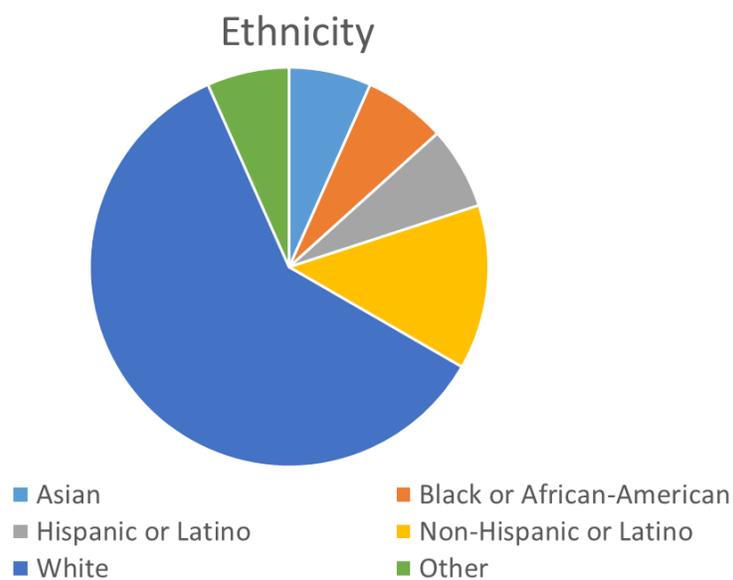


Figure 1. Graph of participant ethnicities, n = 13.

Interview Data

After data immersion, the researcher identified three themes and 12 sub-themes (see Table 3). The quote that encapsulated this project was from Participant 20, who stated, "...we're making it work because we don't have any other options, so we're making it work". School nurses are working with limited support and resources while trying to provide safe, adequate care to schoolchildren. The following section will discuss each theme and sub-theme related to the barriers school nurses face when providing T1D in the school setting.

Table 3

School Nurse Barriers to Type 1 Diabetes Care – Themes and Subthemes

Theme	Subtheme
Care Coordination	Advocacy
	Supervision
	Case management
	Workload
Communication	Provider
	Children
	Parents
	Staff
Parents	Emotional response
	Inability to make appointments
	Finances & supplies
	Knowledge deficit

Care Coordination

The school nurse participants felt that the biggest barrier to providing T1D care in the school setting was difficulty with care coordination. Care coordination includes: a) managing students with and without chronic conditions, b) educating children, parents, school personnel, and school administrators, c) coordinating communication and care plans across interprofessional teams, and d) delegating appropriate tasks to trained personnel (NASN, 2016). One school nurse described care coordination for a child with T1D as:

...it's a bit of a circus getting it all accomplished...so that's a little bit stressful...so figuring how all the coverages work, has been challenging and exhausting at times...but definitely a learning process for me...

(Participant 15)

School nurses must advocate for support, supervise licensed and unlicensed personnel, manage each child with T1D, and prioritize tasks based on their workload. The researcher identified the following sub-themes related to care coordination: advocacy, supervision, case management, and workload.

Advocacy

The participants felt that advocacy was an important part of their role in care coordination for children with T1D. The participants reported the need to advocate for more nursing services and/or support services for children with T1D who needed consistent supervision. One school nurse said:

...I actually petitioned with the school superintendent...and he went before the board and they actually hired a resource aid specialist...but we were actually able to get an RN in that position...so she is at the school site, administering insulin to the TK [transitional kindergarten] student and oversees the lunchtime administration...on the other student. (Participant 3)

The participants also encountered frustration when advocating for support services. Many school nurses are the sole health professional on a school site. The school nurse must advocate for additional health services when needed but the participants reported difficulty when advocating for services. One school nurse described his/her experience as:

...it's like the school nurse is the bully, and is uncooperative, and not part of the team because she doesn't agree...And...I always go back to in the clinical setting, what's required to even administer just a dose of insulin to someone...it takes two licensed people to look it over and agree that that's correct and it can ultimately kill you. (Participant 2)

Participants highlighted the gravity and potential risk of providing T1D care in the school setting.

Supervision

The participants felt the aspect of supervision presented a barrier to providing T1D to children. Some participants utilized either RNs or LVNs to provide direct care to children with T1D. In the school setting, the school nurse must supervise the person providing T1D care even if that person is an RN or LVN. The participants who utilized RNs or LVNs felt comfortable delegating T1D care. Participants voiced that without the use of RNs, LVNs, or UAPs, they would not be able to provide T1D care as children with T1D need care at the same time of day (e.g., lunchtime). One school nurse said,

...because without them [LVNs] I really would feel ... like if it was just the credentialed nurses...I have my three sites, I don't know what I would do...there is no way I could provide proper care for them... (Participant 11)

Other participants utilized UAPs to provide daily T1D care and/or be prepared to intervene in a T1D emergency. One participant felt that if he/she did not have LVNs:

...I would almost have to delegate to unlicensed [personnel]...but to me, I've been in so many situations where I've had to use my nursing judgement on how to dose them or what to do...they're low when they're going to PE [physical education] or...they're having a party randomly and how are you going to look up the carbs really quick but wait they've already been dosed...just crazy things that you have to use your nursing judgement for which I don't think an unlicensed person...should be given that responsibility... there's too much at stake. Too many things could go wrong...[if] they dose them wrong...[then] they can kill the kid.

(Participant 11)

Again, participants stressed the gravity and potential risk of providing T1D care in the school setting as it relates to supervision.

Case Management

Another barrier that the participants discussed was the aspect of case management. School nurses must manage each child with T1D; case management includes identification, assessment, coordination, intervention, and evaluation (NASN, 2016). Although the process of case management focuses on the individual child with T1D, school nurses must also manage the overall care plan, which includes the parents and healthcare provider.

School nurses encounter barriers when trying to provide case management to children with T1D, as there can be sudden changes in the DMMP. One school nurse described case management as:

Sometimes we have the DMMP, the diabetic medical management plan and it's followed to the T...[sometimes] it's on the DMMP that the parent is allowed to not go by...the sliding scale and...the carb count, the parents [are] allowed...to make changes verbally. So...in those situations...it's good...that I'm there or we can collaborate more and...discuss if any other issues come up, if they're really high or really low, it's a good collaboration we can work on it and...take care of the... student safely. (Participant 18)

School nurses are responsible for providing consistent case management to each child with T1D. Case management is a complicated, on-going process that can present barriers to school nurses who have limited resources and high school nurse to student ratios.

Workload

As a result of a school nurse to student ratio of 1 to 2804, the participants discussed the difficulty with providing care coordination to children with T1D. School nurses must prioritize nursing tasks on a daily basis based on emergent needs, a child's needs, available resources, and available personnel. When asked about how the school nurse to student ratio affected care, one participant said:

And...so you have to triage. And you have to determine: what is the most important priority right now?...the emergent thing is...if there's an emergency thing I'm going to focus on that. So yeah, you can only have so much time for these things...and you do your best... (Participant 22)

With an increase in the school nurse to student ratio, an increase in children with T1D, and the complexity of T1D care the school setting, participant 2 said, "You get up in the morning and think: do I want to do this again?" This quote

exemplifies the barriers and the stressors school nurses in California encounter on a daily basis.

Communication

Another barrier that the participants discussed was the difficulty maintaining communication between the healthcare provider, the child with T1D, parents, and school personnel. The school nurse must effectively communicate with the above parties in order to deliver T1D care to each child. The communication process is complex but limited resources and a high school nurse to student ratio create additional barriers. One school nurse described the communication process as:

And then being able to communicate medical information back and forth from the parent to me and then me to the parent and then to the school. That's probably the biggest barrier. (Participant 8)

Provider

The participants highlighted the stressor of communicating with the healthcare provider. School nurses must be able to communicate with healthcare providers in order to provide T1D care in the school setting. Overall, the participants voiced their concerns about not feeling like an integral part of the healthcare team related to a child's T1D care. As the school setting differs from a hospital or clinical setting, it is important for healthcare providers and school nurses to establish streamlined communication; this is often not the case. One school nurse described her experience as:

Sometimes I'll hear back, sometimes I won't...I get frustrated...as a school nurse at the fact that the physician isn't following up...I'm not in the loop.

School nurses are not in the loop on what's actually going on... (Participant 2)

Children with Type 1 Diabetes

School nurses are also responsible for fostering open communication with the child with T1D. A child's routine and lifestyle changes after the diagnosis of T1D. In order to ensure consistent care, school nurses must establish a relationship of trust, respect, and open communication with the child with T1D. One school nurse described the importance of establishing a trusting relationship with a child with T1D:

...I think one of the things that stands out to me most caring for a student with diabetes is the emotional weight that just having type 1 presents for the child...if she had a choice she would not come in to the office every single day, miss out on part of her recess, get the last table at the lunch table, you know the kinds of things that are very important to a 5th grader...whatever I can do or say to make her office visits more comfortable is really important to me, because I think that's a big part of caring for the whole child. (Participant 17)

The communication between the school nurse and child with T1D can also be a barrier. The school nurses described the difficulties with implementing a consistent T1D care plan while also maintaining a trusting relationship with a child with T1D. One school nurse described the barriers as:

I'm walking this ...little tightrope where I do need them [child with T1D] to know that they need to be consistent, they need to...come in...they need to follow orders, the orders that the doctor has written...and that they need to be open with me about those things but then at the same time

also...showing them that I respect them and that I don't look down at them... (Participant 10)

Parents

Any pediatric healthcare provider is aware of the importance of communication with the child's parents and/or guardians. School nurses must communicate with a child's parents frequently in order to provide thorough, consistent T1D care. Although parents are an integral part of a child's T1D care, parents can also present challenges when school nurses are attempting to communicate with them. As children spend a majority of their time at school, it is important for the school nurse to be able to maintain communication with the parents in case the school nurse needs clarification or if the child needs to be sent home.

The participants discussed how some parents wanted to be contacted frequently whereas other parents did not want to be contacted about the T1D care provided at school. Another communication barrier that the school nurses discussed was difficulty trying to contact the parents. One school nurse described his/her difficulty with contacting parents as:

...several of our student's parents work...in the agricultural industry so they are very difficult at times to get ahold of...the student should go home and many times we cannot get ahold of those parents. (Participant 20)

School Personnel

As stated above, a school nurse relies on a variety of school personnel to carry out day-to-day T1D or to be prepared for a T1D emergency. The school nurse needs to establish open communication with school personnel, regardless of how involved that person is in the T1D care of a child. Most school personnel

have job responsibilities that do not include providing T1D care to children. Some school districts hire personnel specifically for providing T1D care to a child but most school personnel volunteer to provide T1D care, in addition to their other job duties. As a result, the communication between the school nurse and school personnel can become a barrier to care. One school nurse said:

...and because they are the secretary, they are doing a hundred other things, and they didn't get back to me to ask me about it until the day I was there, which in some cases can be REALLY dangerous, and so very concerning to me because it's my license, and my care of the student and I care very much for these students to be safe and able to participate in their learning...

(Participant 15)

Parents

The last theme the researcher identified was how the parents were a barrier to providing T1D care to children. Parents can have a variety of responses to a chronic condition diagnosis in their child. The school nurse must navigate through the parental responses to the T1D in their child in order to establish a relationship with the child and parents. Participant 21 described how a parent's reaction was a barrier to care as "...in the beginning especially when they're brand new then there's a lot of fear that the parents have and sometimes...they can take that out on the school a little bit."

Emotional Response

Parents can have a range of emotions related to the diagnosis of T1D in their child. Many participants recognized the emotional toll that having a child with T1D has on a parent and the overall family's lifestyle. Parents feel stressed about having to keep their child's blood glucose within a certain range; a low

blood sugar can be a life-threatening emergency and a high blood sugar is also an emergency. Participants discussed how the parental fear of a low blood glucose impacted the care of a child with T1D. Some participants highlighted how parents preferred that their child's blood glucose to run high; other participants discussed how fearful parents were of a low blood glucose. One school nurse described the parent's emotional response as:

...the whole household fell apart at that point. The parents just couldn't handle it and they couldn't handle his behaviors and they were afraid he was going to be quote end quote "dead in the bed." And they used to tell him...you can't do this because you're going to be dead in the bed. We're going to check in and you're going to be dead in the bed, and they kept saying this. (Participant 9)

Inability to Make Appointments

Another important element to T1D care is consistent follow-up with a child's healthcare provider. On average, a child with T1D has a regular office visit with their specialty care provider every six to 12 months, which does not include emergency or unplanned visits. It is important for children with T1D to be regular seen by their specialty care provider as a child's growth and development can affect their T1D care plan.

It can be difficult for parents to keep appointments, due to transportation, finances, or their job. School nurses face barriers when parents are unable to make appointments for their child with T1D, as the school nurse needs an updated T1D care plan every year. One school nurse described a parent's inability to make T1D appointments as:

...this little gal has not been back to her provider since her diagnosis...I don't believe that the mother drives. And the dad works full time. And so...it comes down to...do I work and keep my job or do I ask for time off...and take my kid to appointments. And I think their interpretation is ok her needs are being met because we are in contact with all of the providers and we are making the adjustments in her coverage care...for insulin. And...so, I think the parents just feel that all her needs are being met. So there's not that sense of urgency, on their part, to...carry out responsibility on their end. (Participant 20)

Finances and Supplies

Another barrier the participants identified related to parents was the financial burden of having a child with T1D. School nurses work closely with the parents to establish and provide T1D care in the school setting. Due to this relationship, school nurses are aware of the various stressors parents encounter when trying to manage a child with T1D, including a lack of financial resources. Participant 7 stated, "And they [the parents] don't have the financial resources...to...access things...that maybe that other people would utilize and so, you know sometimes when I'm asking for things I feel like I'm burdening her..."

School nurses rely on the child's parent to provide all the T1D equipment and supplies. If a parent does not bring in the required supplies, a school nurse has limited to no access to additional T1D supplies, whereas a nurse in a hospital or clinical would have access to T1D supplies. One school nurse described the barrier of supplies as:

...I had...told mom...he had no ketone strips...his lancets and...needle pens were in zip lock bags ...the best I could do was try to relate to the

parent....more than likely...mom is having to separate the supplies, and you know keeping certain ones at home and keeping ones at school.

(Participant 12)

Knowledge Deficit

When a child is diagnosed with T1D, the parents must learn about how to treat and incorporate T1D care into their daily routine and life. As the school nurse establishes a relationship with the family, the school nurse assesses the T1D knowledge of the parents and child with T1D. The participants discussed how a parent's T1D knowledge deficit was a barrier to T1D care as there were discrepancies between a school nurse's T1D knowledge level and a parent's T1D knowledge. The school nurse must cultivate the relationship with the parent so both parents feel comfortable sharing their T1D knowledge to reduce knowledge deficits. One school nurse described a parent's knowledge deficit as:

And then...parents understanding it [T1D] completely. Sometimes they don't get the education through their diabetes care team. Like it's kind of a rush one day visit and...they don't really understand so I think those are the two top barriers...they get this education crash course over a couple days and then they're expected to be able to manage these students and know what to do and...it's just difficult. (Participant 11)

Through the interviews, the participants described the difficult and dynamic barriers to providing T1D care in the school setting. School nurses had difficulty communicating, difficulty coordinating care, and difficulty supporting parents regardless of their practice setting. School nurses, healthcare professionals, school personnel, and parents can use the above themes and subthemes to reduce the barriers to providing T1D in the school setting.

CHAPTER 5: CONCLUSION

This study was a unique assessment of the barriers to care that school nurses in California encounter when trying to provide T1D care to children. School nurses are the link between healthy children, schools, and the healthcare system. School nurses need additional resources to provide safe, effective care in the school setting. Throughout the interviews, the school nurses exemplified how resilient and passionate they are about providing care to children.

Limitations

There were potential limitations as the researcher used a purposive study design. The participants were newer school nurses, with an average school nurse career of 4.46 years. For a robust qualitative study, the participants should represent a range of school nurse experience as the perception of barriers to T1D care may change throughout a school nurse's career. Another limitation was that there was limited ethnic diversity as a majority of the participants identified as white or Caucasian.

There were also potential psychological risks due to the potential stress of discussing the difficulties of care coordination and chronic care management in the school setting. As the researcher is a faculty member in the school nurse credential program, participants may have under reported the barriers to providing care as they may see it as a reflection of their school nurse practice. Participants could possibly be current or former students of the researcher. To mitigate these potential problems, the school nurse credential program coordinator sent out the recruitment emails and the researcher used a graduate research assistant to conduct the interviews. The research assistant possessed the following qualifications: a)

completed qualitative researcher training with the researcher, and b) completed either the NIH human subjects tutorial.

Future Implications

Participants were able to share their experience of T1D care in order to help improve future care coordination for children with T1D in the school setting. As school nurses care for a wide range of children (i.e., children with acute, chronic, or no conditions), future studies should assess how school nurses in California coordinate care for all children on their caseload.

Healthcare agencies, school districts, providers, school nurses, and families can use the results of the study to improve care coordination for children with T1D in the school setting. The results can also be used to advocate for a lower school nurse to student ratio based on the stressors school nurse experience in California. The results of this research project will provide the school nurses, school districts, and other health care providers with necessary information that will help improve care coordination to children with T1D.

Current and future school nurses can use the study results to understand the unique characteristics of providing T1D care to children in the school setting. Nursing organizations, as well as school nurse credential programs in California, could use the study to help inform and prepare school nurses for the important task of care coordination of T1D in the school setting. The results of this study could also be used to advocate for more coordinated care between healthcare systems and the school setting.

School nurses in California are “making it work because we [school nurses] don’t have any other options, so we’re making it work” (Participant 20). School nurses are a passionate, resilient part of the healthcare team and should be

recognized for the important role they have in caring for a child's health. School nurses need additional support and resources in order to reduce barriers to providing care to children in the school setting. Children are our future and school nurses are passionate about providing safe, effective care to children.

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APPENDICES

APPENDIX A: INTERVIEW QUESTIONS

INTERVIEW QUESTIONS

School Nurses' Experience of Barriers to Care in Children with Type 1 Diabetes

Introduction: Hello and thank you for participating in this research study. For transcription and note-taking purposes, I would like to digitally record the interview today. The only people who will have access to the recordings are the researchers on this study. The recordings will be destroyed after they are transcribed.

The interview process will take approximately an hour. During this interview, I have a few questions that I would like to ask.

Grand tour question: Tell me about your experiences of barriers to providing care to children with type 1 diabetes in the school setting.

Probes:

- a) Tell me about your experiences providing care to children with type 1 diabetes in the school setting.
- b) Tell me about the barriers to providing care to children with type 1 diabetes in the school setting.
- c) Is there a time when these barriers were minimal or non-existent?
- d) Tell me about your experiences interfacing with healthcare providers.
- e) Tell me about your experiences interfacing with parents and/or guardians.
- f) How many students with type 1 diabetes are on your caseload?
- g) What is the grade range of your students with type 1 diabetes?
- h) Tell me about your experiences about the school nurse to student ratio and how it affects the care of students with type 1 diabetes.
- i) If you supervise personnel for students with type 1 diabetes, how does the supervision of registered nurses, licensed vocational nurses, or unlicensed assistive personnel influence your role in care coordination?
- j) What recommendations or resources have been helpful in your school nurse practice related to providing care to students with type 1 diabetes?
- k) Is there anything else you would like to share with me?
- l) May I contact you with any follow-up questions or clarifications?

This concludes the interview. Thank you so much for your participation in this study.