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Raising Children with Type 1 Diabetes and Celiac Disease:
Parental Experiences

Kerri Trump Erickson

A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of
Master of Science

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College of Nursing
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ABSTRACT

Raising Children with Type 1 Diabetes and Celiac Disease: Parental Experiences

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The purpose of this qualitative descriptive study was to examine parental experiences and challenges raising children with both T1DM and CD. Twenty-six families, including 30 parents (25 mothers, 4 fathers, and one custodial grandmother), participated in a 30-60 minute audio-recorded interview designed to explore parental experiences raising children with both T1DM and CD. Participants were asked IRB approved open-ended questions about their experiences raising a child with both diseases. Direct quotations best representing categories/sub-categories were identified through selective coding. Analysis revealed seven main themes: Six themes parents are concerned about, including (a) their child's health complications, b) the challenges of daily disease management, c) the time, resources, and expense required to manage both diseases, d) their child's emotional/mental health, e) support from healthcare providers, f) community support/understanding, and lastly (observed by the researcher) g) how positive versus negative experiences and adaptation influence the way parents and children meet their challenges and perceive the future. Parents raising children with both T1DM and CD face many daily challenges as they learn to manage both lifelong chronic diseases. They need access to and support from healthcare providers for up-to-date education, treatment options, and community resources. Positive provider relationships were identified as: being responsive to parent's questions, willing to listen to parents, creating an open and honest dialogue with parents, having a personal relationship with the child, and being a patient advocate. Future research should examine broader ethnic and socioeconomic populations. A quantitative study design could also be used to assess the level of caregiver burden, in order to compare different ethnic and socioeconomic groups.

Keywords: mothers, fathers, children; parental experiences; type 1 diabetes; celiac disease, qualitative research, nurse practitioner

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My biggest debt of gratitude I owe to my loving and supportive husband, Jon, my mother, and my five children who have sacrificed the most for me to further my education! Thanks to my brother's family whose experiences with type 1 diabetes and celiac disease were the inspiration for my research.

A big "thank you" to the parents and families who shared their precious time and personal experiences! Visiting with these families was a memorable, valuable learning experience. The following quote captures the essence of the burden carried by parents raising children with type 1 diabetes and celiac disease, as shared by the mother of a 12 year-old daughter (three years after her dual diagnosis):

"It's a disease that never sleeps, both of them, ... and as a parent you have to learn to live with that 'cause it's kind of just like a fire burning in your home and you have to keep it under control and learn to live with it and monitor it, keep it in check. Otherwise it could get out of control really fast."

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Raising Children with Type 1 Diabetes and Celiac Disease: Parental Experiences

Caring for a child with a chronic illness places emotional, psychosocial, and financial burdens on the family, particularly parents, as they meet the health related needs of their ill child. When the child has type 1 diabetes mellitus (T1DM) these burdens can be especially challenging, and T1DM is one of the most common chronic illnesses diagnosed in childhood (Mitchell et al., 2009). Celiac disease (CD) is an autoimmune condition associated with T1DM (Bhadada et al., 2011). When these two diseases occur in the same child, the parents' concerns are compounded, especially related to the need for special diets (Samasca, Iancu, Butnariu, Andreica, & Dejica, 2011). However, there is little information in the literature discussing experiences and needs of parents raising children with both T1DM and CD, since studies discussing the two diseases focus primarily on the prevalence, association, and risks of individuals with T1DM or CD also having the second disease (Bhadada et al.; D'Annunzio et al., 2009; Larsson et al., 2008; Maglio et al., 2009; Mojibian et al., 2009; Mysliwiec, Balcerska, Zorena, Mysliwska, & Wisniewski, 2008; Samasca et al.; Simell et al., 2010; Smyth et al., 2008; Sumnik et al., 2006; Uibo et al., 2011; Warncke et al., 2010).

It is indeed important to learn about parental perceptions and experiences raising a child with T1DM and CD because they face multiple challenges as they learn to manage their child's long-term healthcare needs. Specifically those challenges relate to needing a structured eating schedule, monitoring carbohydrate intake, limiting intake to only gluten-free foods (without wheat, rye, or barley derivatives), monitoring blood glucose, administering appropriate insulin doses, and adjusting daily insulin doses according to changes in appetite, exercise, or illness (Chase & Eisenbarth, 2011; Crandall, 2011; Ruiz, 2011; Sundaram, Hoffenberg, Kramer, Sondheimer, & Furuta, 2011). Raising a child with either T1DM or CD can be time-consuming

and stressful for parents, but raising a child with both diseases increases stress and care-giving levels (Samasca et al., 2011). Therefore, the purpose of this project was to learn more about parental perceptions and challenges faced when raising a child with T1DM and CD.

Literature Review

This literature review initially describes T1DM and CD. The association between T1DM and CD follows, as does a review of the scant literature on parental perceptions regarding raising a child with both T1DM and CD.

Understanding Diabetes Mellitus

Diabetes is a chronic disease with high levels of blood glucose, due to either lack of insulin production (T1DM) or insulin resistance by the cells in the body, as in type 2 diabetes (PubMed Health, 2012a). About one in every 400 youth have T1DM and the prevalence of both types of diabetes in the United States is 25.8 million (8.3% of the population), according to the CDC (2011).

The exact cause of T1DM is unknown; however, it is believed to be an autoimmune disorder triggered by an infection or another process causing the body to mistakenly attack insulin-producing pancreatic beta cells (PubMed Health, 2012a). Without enough insulin, glucose builds up in the bloodstream leading to symptoms of diabetes including extreme thirst, hunger, fatigue, blurry eyesight, numbness or tingling in the feet, unintentional weight loss, and frequent urination. Untreated, very high blood glucose levels lead to diabetic ketoacidosis expressed as nausea, the inability to keep fluids down, flushed face, rapid breathing, fruity breath and dry skin (PubMed Health, 2012a). If left untreated, severe ketoacidosis, can progress to cerebral edema, coma, and death (Chase & Eisenbarth, 2011; Crandall, 2011).

Years of hyperglycemia can lead to multiple complications affecting both small and large blood vessels. In fact, the three most common and devastating complications of T1DM are related to microvascular disease: (a) blindness, (b) kidney failure, and (c) peripheral nerve damage (Chase & Eisenbarth, 2011; Crandall, 2011). Damage to small blood vessels can also impair healing of minor breaks in the skin, leading to deep ulcers and serious infection. The average medical expenses for a person with the disease are at least double that of a person of similar age but without the disease; the overall risk of death for a person with T1DM is twice that of a person of similar age with other risk factors in common (CDC, 2011).

Since T1DM is a lifelong disease without a known cure, the only treatment is daily insulin administration by subcutaneous injection, one dose at a time, or by continuous pump infusion (with site changes every three days). In addition to insulin administration, management of T1DM in children and adolescents must also include a regimented eating schedule (to prevent extremely high or dangerously low blood glucose levels), strict monitoring of carbohydrate intake (known as carb counting), and adjusting of insulin dosing with increased physical activity, illness, and sometimes during sleep (Chase & Eisenbarth, 2011). Such close regulation and monitoring throughout the day and night, can be overwhelming and exhausting for parents.

Understanding Celiac Disease

CD is an autoimmune disorder of gastrointestinal malabsorption, affecting approximately 1% of the population and “is one of the most common lifelong conditions in the United States” occurring in genetically predisposed individuals (Gainer, 2011, *Introduction*, para. 1). Known high-risk populations for CD include first-degree relative of individuals with CD (10% prevalence), second-degree relatives (2.6% to 5.5% prevalence), and individuals with iron

deficiency anemia (IDA). Individuals with chronic intestinal symptoms also have approximately 10% to 15% higher incidence of CD (Gainer).

CD causes problems with small bowel absorption of nutrients in foods important for good health (PubMed, 2012b). Consuming gluten-containing foods triggers an immune-mediated response to gluten (a protein complex found in wheat, barley, and rye), stimulating antibody production that attack intestinal villi. This response causes inflammation and damage to the small intestine, leading to illnesses associated with malabsorption and malnutrition (Gainer, 2011; Ruiz, 2011; Westerberg et al., 2006).

CD symptoms include diarrhea, abdominal pain from bloating, gas, and indigestion, decreased appetite, lactose intolerance, nausea, vomiting, “fatty” stools that float, bloody stools, or unexplained weight loss. According to Gainer (2011) it is not a rare disease, but can take up to 10 years for those with symptoms to be diagnosed, because these symptoms can be associated with other diseases of the gastrointestinal tract. Additional symptoms seen in children include defects in tooth enamel, changes in tooth color, behavior or mood changes, fatigue, poor weight gain, slowed growth, delayed puberty, shorter than normal height for age, anemia, vitamin B12 deficiency, osteoporosis (from malabsorption of calcium and vitamin D), vitamin K deficiency (leading to GI hemorrhage, bloody nose, blood in urine, or cutaneous bleeding), and dermatitis herpetiformis - a severe itchy, blistering skin rash usually seen on the buttocks, elbows, and knees (Amerine, 2006; Gainer; PubMed Health, 2012). According to McGowan, Castiglione, and Butzner (2008), many children with unusual gastrointestinal presentations and those high-risk groups with mild symptoms can be identified through serological testing.

The only treatment for CD is strict adherence to a gluten-free diet; but lifelong adherence to a strict gluten-free diet can interfere with work and social life, and be very expensive and

difficult to maintain (Gainer, 2011). This can be a tremendous burden on parents and families raising children with CD, since gluten is found in up to 70% of manufactured food products and manufacturing regulations are inconsistent between countries (Garcia-Marnzanares & Lucendo, 2011). Fresh fruits and vegetables are usually considered safe, as well as rice flour and cornmeal (if not exposed to other flours made with gluten-containing grains). However, the risk of exposure to gluten when eating away from home can be a big concern because of cross-contamination of foods being prepared together in kitchens that are not completely gluten-free (Gainer).

Besides problems of exposure to foods containing gluten, there are other potential threats to individuals with CD. Specifically, Gainer (2011) noted challenges of observing a strict gluten-free lifestyle because there are many potential gluten exposures other than what is in food, such as vitamins, teas, supplements, lipsticks, lip balms, and adhesives on envelopes and stamps. Even the arts and crafts supplies children use may be a source of gluten exposure, particularly if children do not wash their hands thoroughly before eating a snack or meal. Severe illness and complications can develop from untreated CD (due to malabsorption of nutrients) including: stunted growth, fragile bones, anemia, fatigue, hair loss, rashes, bleeding tendencies, and mood/behavioral changes. Therefore, it is important for children at risk (including those with T1DM) be diagnosed early through serological screening tests and a biopsy (Gainer; Larsson et al., 2008; Samasca et al., 2011).

Understanding the Relationship Between T1DM and CD

The association between CD and T1DM has been recognized for more than 40 years, due to shared common gene alleles. Patients with T1DM are more prone to have CD, although the evolution of CD is often without any clinical symptoms (Mahmud et al., 2005; Samasca et al.,

2011; Smyth et al., 2008). Complex pathological mechanisms including genetic susceptibility, environmental exposure, alterations in intestinal permeability, and auto-immune responses play central roles in each disease (Mysliwiec et al., 2008; Uibo et al., 2011). In autoimmune diseases, the body mistakes its own cells as foreign invaders and destroys them. Interestingly, T1DM and CD are often diagnosed about the same median age in children with conferred genetic risk for both diseases (Simell et al., 2010). In fact, a diagnosis of CD and the presence of antibodies suggestive of CD occur more frequently in patients with T1DM than in the general population, with the incidence ranging from 9.2% (Samasca), to 10.7% (Larsson et al., 2008; Warncke et al., 2010) and as high as 11.1% (Bhadada et al., 2011). This means for every 100 children diagnosed with T1DM, 10 of them will also have CD.

Experiences Raising a Child with T1DM

Several studies discuss parental experiences raising children with T1DM (Cogen, Henderson, Hansen, & Streisand, 2007; Freeborn, Loucks, Dyches, Roper, & Mandelco, 2013; Howe, Ayala, Dumser, Buzby, & Murphy, 2012; Mednick et al., 2010; Mitchell et al., 2009). Scholes and colleagues (2013) studied adolescents with T1DM. One factor identified as influencing metabolic control was parental support and involvement in disease management. Freeborn and colleagues (2013) discovered parents raising children with T1DM experienced feelings of grief, loneliness, and the need for emotional support while coping with the daily challenges of caring for a child with T1DM. In the same study, parents were fearful of allowing the child to go anywhere without them; parents felt “burned out”, sad because they were not able to take family vacations anymore, overwhelmed with responsibilities of managing the disease, and concerned about long-term complications, and difficulties associated with controlling the disease on a daily basis. Howe and colleagues (2012) investigated what parents of children with

T1DM want and need from their healthcare providers. They discovered parents appreciate a provider being mindful and present at clinic visits, working to develop a relationship with their child, and assisting them make informed decisions and develop a treatment plan that works with the family's lifestyle.

Experiences Raising a Child with CD

No studies were found examining parental perceptions raising a child with CD. However, two studies examined the perception and social challenges of teenagers with CD (Olsson, Hornell, Ivarsson, & Snyder, 2008; Olsson, Lyon, Hornell, Ivarsson, & Snyder, 2009). Understanding such perceptions and social challenges could possibly influence how parents respond to their children with CD and help them manage their disease. Specifically, Olsson and colleagues (2008) identified various dilemmas related to limited accessibility of gluten-free food and unmet needs of adolescents requiring a gluten-free diet for optimum clinical outcomes. Olsson and colleagues (2009) discovered adolescents with CD experienced the "stigma" of needing special meals everywhere they went, leading to a sense of inequality, embarrassment, anger, alienation, guilt, and a sense of discrimination. They often found gluten-free foods were unavailable wherever they went and appeared different than gluten-containing foods (Olsson).

Purpose / Aim

The purpose of this study was to investigate parental experiences of raising a child with T1DM and CD, by using a qualitative descriptive design. Refer to Appendix A for interview questions.

Methodology

Design

This study is a qualitative descriptive design examining parental experiences raising children with both T1DM and CD.

Participants

Twenty-six families, including 30 parents (25 mothers, 4 fathers, and one custodial grandmother) of children with T1DM and CD participated. Families were recruited through the Primary Children's Medical Center Diabetes Clinic in Salt Lake City, Utah; Utah Valley Regional Medical Center in Provo, Utah; and the St. George Clinic at Dixie Regional Medical Center in St. George, Utah.

Family ethnicity were Caucasian (n=25; 96%) and Hispanic (n=1; 4%), with all families living in the western United States. Most children (89%) were living in a two-parent home (n=24), one with a step-parent; only two children (7%) were being raised by a single mother and one child (3.7%) was being raised by the grandmother who legally adopted the child. The average age of fathers was 44 years, with a mean education of 14.0 years and average hours employed each week was 41.4 hours/week. Mothers were on average 42 years of age, with a mean education of 14.6 years and worked an average of 23.1 hours/week (ranging from 0 to 55 hours/week). The number of children in each family ranged from one child to nine children ($M = 3.7$) and the ages of the children with T1DM and CD ranged from 6 to 19 years, with the average age being 12.6 years. Most (80%) children were female. The mean age of the children at diagnosis of T1DM was 6.7 years and the mean age at diagnosis of CD was 8.8 years. Only three of the children were first diagnosed with symptomatic CD and subsequently developed T1DM, within 6 months to 4 years of CD diagnosis. Thus, most children were initially

diagnosed with T1DM and routinely screened and found to have CD later (some within a few weeks or months of T1DM diagnosis, others were not diagnosed with CD for 6-9 years). See Table 1.

Procedures / Setting

After IRB approval and obtaining consent, parents completed a family demographic questionnaire (see Appendix B) and then were interviewed for 30-60 minutes about their perceptions of raising a child with both T1DM and CD. Participants were asked IRB approved open-ended questions including how T1DM and CD affected their family and day-to-day life; (a) their experiences raising a child with both diseases, (b) experiences with healthcare providers, (c) primary concerns and biggest challenges raising their child, and (d) social support they receive from extended family and community (see Appendix A). Attempts were made not to influence answers but rather allow parents to talk freely about their experiences. Further questions were asked if clarification was needed. Each participant received a \$20.00 gift card as compensation. The interviews were digitally recorded and transcribed before being deleted.

Qualitative Analysis

The digitally-recorded interviews were transcribed verbatim and entered into NVIVO 9 for data storage and management. The transcriptions were then examined for patterns and themes according to qualitative methodology (Denzin & Lincoln, 2000). Themes were sorted into categories and direct quotes best representing the categories and sub-categories were identified through selective coding. To assure trustworthiness, interviews were reviewed and discussed until consensus was reached. An investigator who did not participate in the analysis reviewed the themes, to ensure interviews and quotes correctly reflected the themes (Denzin & Lincoln).

Results

Analysis of parent interviews revealed seven main themes: parents are concerned about (a) their child's health complications, b) the challenges of daily disease management, c) the time, resources, and expense required to manage both diseases, d) their child's emotional/mental health, e) support from healthcare providers, f) community support/understanding, and lastly (observed by the researcher) g) how positive versus negative experiences and adaptation influence the way parents and children meet their challenges and perceive the future. Refer to Table 2. A discussion of the themes follows.

Health Complications

Each parent identified both long-term and short-term complications of T1DM as their biggest concern, particularly those related to vision loss, kidney failure, not being able to have a baby, or having a limb amputated at a young age. One mother of a 16-year-old daughter (diagnosed with T1DM at age six and CD at age 15) explained,

I want her to have a full life. I want her to get married and have babies and be happy....

I want her to live past 25 and still have her foot and not have to have a colostomy bag....

Another one of my fears is with her diabetes, her being alone, going low, and passing out.... I will always worry; at no age will I not worry about her.

Another mother of a seven year-old daughter (diagnosed with T1DM at age four and CD at four and a half) shared her concerns this way,

The biggest concern I would say is her long term health. Just making sure that we're doing what it takes to keep her healthy, in the long term, and not have those bad side effects.... Taking care of herself now is what's going to take care of her in the future, having kids, and being that responsible adult.

Parents also expressed concerns about short-term complications. For example, if the child receives too much insulin for the amount of food digested the blood sugar could bottom out and result in seizures or a coma. Many parents were concerned their child might be alone when this happened, or else no one would know what to do if the child's blood sugar went too low. The mother of four children with T1DM, including a 14-year-old daughter (diagnosed with T1DM at age 18 months and CD at age eight) said, "I worry for them when I'm not the one in control.... I worry she'll be somewhere and she'll go low, and nobody will know what to do."

Challenges of Daily Disease Management

Both T1DM and CD are chronic conditions that will never go away. Disease management requires constant vigilance, awareness, and attention by the parents and child over the course of the child's life. Both parents and children are exhausted with the reality of having to worry about the inconveniences required to stay healthy.

Immediate challenges of day-to-day management of both diseases center around meal times, concerns over providing healthy gluten-free food, and accurately calculating the right amount of insulin required for carbohydrates ingested. This was especially difficult soon after the initial diagnosis, when families were still learning about each disease and management refinements. One mother of a seven year-old daughter (diagnosed with both diseases between ages four - four and one half) made this comment,

I felt like I didn't even know what to feed her. I was still kind of getting down the particulars of the diabetes and then having that (CD) on top of it, it was really overwhelming. That was, I think, one of the hardest years of our life.

The mother of a twelve-year-old daughter (diagnosed with T1DM at age nine and CD at age nine and one half) summarized the day-to-day challenges well: "Our whole family has had

to change and alter the way we do things.... It changes your whole life, your whole family, your whole future, where you go, when you go.” This mother went on to describe a recent family vacation and difficulties faced,

We went on spring break and her pump stopped working and so for two days of spring break we were not enjoying our vacation and having fun, we were dealing with pumps and needles and trying to track down different insulins and verifying it was the pump and not the insulin. And then these times you’re still trying to figure out food, I mean it’s impacted our extended family and everywhere we go... every activity, every vacation, everything you do it directly impacts the family, but yet you learn to accommodate it.... It does get irritating sometimes, but at the same time you don’t have a choice.

Parents of a six year-old son (diagnosed with CD at age 17 months and T1DM at age two) and a nine year-old son with T1DM said,

[Mother] I can say that everything we do is a challenge. Everywhere we go we have to plan ahead because he has diabetes, so you have to have for lows to bring food just in case you decide to stay longer.... *[Father adds]* When we try to go on a family trip for a few days just to get a break, you’ve got to pack your silverware, crockpot, things to cook, because number one you don’t know where you’re going if they have gluten-free, if they do, can you trust it? ... It’s a lot of work to just get anywhere....

The mother of a 14-year-old daughter (diagnosed with T1DM and CD at age ten) expressed her own struggle with the CD diagnosis,

Those first six months or so, it was frustrating.... I spent a lot of time crying in the grocery store.... It was totally overwhelming... wandering through the grocery store,

wondering, ‘what in the world am I going to feed this child?’ How does she eat from here on out?

Another mother of a 14-year-old daughter (diagnosed with T1DM at age 18 months and CD at age eight years) described her daughter’s challenge this way,

I think she just gets tired. Because she’s tired all the time of dealing with her diabetes and then when you add on top of that the celiac and you go to your friends’ houses and you can’t eat anything and you go to birthday parties and you can’t eat anything, you go to family functions and everything is pasta salad or a cake, or something like that, you go to dinner at a restaurant and they bring hot bread or rolls to your table that smell delicious....

Most parents confirmed CD was more difficult for their child to deal with every day because of the social implications. One mother of a 14-year-old daughter (diagnosed with T1DM and CD at age 10) stated,

It’s hard to send her places, like camp, or really do anything because she has to have her own menu, she doesn’t like to feel different as it is, and now she’s got the extra set of pots, extra set of everything.... We have to have everything be just right. It’s just a lot of extra planning. She does good, but it’s hard.

Time, Resources, and Expense of Managing both Diseases

The insulin and supplies required to administer the insulin several times a day for diabetes management are expensive. The cost of gluten-free foods is also expensive, compared with regular breads, pastas, cereals, and mixes at the grocery store containing gluten. Cost of disease management can be a big concern for families. The custodial grandmother of a 12-year-old granddaughter (diagnosed with T1DM and CD at age 11) stated,

I would worry about kids with these disabilities without insurance because I know what it costs for a pump, I know what it costs for a pump site, I know what it costs to feed a celiac.... I don't know what we would have done. For one thing, she would not have had a pump because they are seven to eight thousand dollars, and her pump sites are forty bucks each and she changes that every three days.

One mother of a seven-year-old daughter (diagnosed with T1DM at age four and CD at age four and one half) said of the expense, "I can't imagine the stress if he (*the father*) wasn't in the military and we had different insurance. The cost would be a big concern."

The mother of a 17-year-old daughter (diagnosed with T1DM at age nine and CD at age 10) said,

I worry that because it is so expensive that she'll try to cut corners, take less insulin, re-use supplies, things like that to save money. And we've told her, if we have to pay for your diabetes the rest of your life we will.... I'm afraid she'll put herself at risk because she won't be able to afford it and she won't ask for help.

Every family mentioned the expense of gluten-free foods, in addition to the cost of insulin and other diabetic supplies. One mother of a 13-year-old daughter (diagnosed with T1DM at age three and CD at age 12) and a 17-year-old daughter with T1DM said,

The biggest challenge we found with the celiac disease has been cost. Everything is so much more expensive when it's gluten-free.... Between keeping up with the insulin and even with good insurance, it still gets to be expensive. And celiac disease has like doubled our grocery bill [*laughs*]. That makes it kind of hard to keep things going.

Another mother explained how she and her 11 year-old daughter (diagnosed with T1DM and CD around age eight) spend a lot of time grocery shopping, in order to find the gluten-free food the

child likes without spending too much money, “We have to go through five grocery stores over five hours so that we’re not spending a total arm and a leg.”

Regarding the time and expense of providing a gluten-free diet, the mother of a nine-year-old (diagnosed in the past year with both diseases) said, “I know some families immediately embrace an entirely gluten-free household, but I didn’t feel like that was the right solution for us, ... it’s cost-prohibitive for a family of our size to entirely go gluten-free.”

The mother of a 12-year-old daughter (diagnosed with T1DM at age two and one half and CD at age six) said,

Celiac is very expensive. The gluten-free foods are about double the price of regular foods.... We were going to put the whole family on the gluten-free diet, but the expense and how much it was going to cost, we were like, no way can we afford it.

To deal with the challenges related to gluten-free foods, most parents have a section of the kitchen designated as “gluten-free only,” which is usually a specific cupboard containing only gluten-free food, as well as a preparation area, a toaster, pots and pans, etc. used for only gluten-free food. One mother of a 12-year-old daughter (diagnosed with T1DM at age nine and CD at age nine and one half) described it this way,

So how we’ve learned to deal with it in our home is I monitor my cooking and I keep my kitchen a certain way and I buy products that I know are gluten-free and yet I don’t cook gluten-free for my whole family, cause I can’t afford it.... We found certain gluten-free products she really likes. We’ve stocked up on and freeze them. When I make brownies for the family that wants regular brownies, she has an alternative and I just keep hers in the freezer and then she has hers while we have ours.

Another mother of 12-year-old daughter (diagnosed with T1DM at age eight and CD at age nine) discussed how much easier it was for her child to accept the diet restrictions once her father started the gluten-free diet. “It’s much easier when more of the family has the disease because then it just makes it part of the routine, versus preparing two different types of meals and so forth.”

Child’s Emotional / Mental Health

It is difficult for a child or an adolescent to stand out as “different” from friends; often children with both diseases feel left out of activities where food is served. One mother of a nine-year-old daughter (diagnosed with T1DM at age five and CD at age seven) stated, “I worry a lot about her emotional health, ... just being difficult when she’s left out at school or other things.”

A mother of a 14-year-old daughter (diagnosed with T1DM and CD at age 10) said,

There’s a part of me that understands ... it’s not a death sentence... it’s not the end of the world, but it is still horribly UN-FAIR. When there is a pizza party at school and she can’t have the pizza... when there is a birthday party and kids bring cupcakes and there is nothing for her to eat.... There have been moments that have been really, really sad and really, really challenging for her.

One mother of a 17-year-old daughter (diagnosed with T1DM at age nine and CD at age 10) said,

I still think for her as a teenager, especially being 17, it’s really hard because she already feels different than her friends because she has to deal with the diabetes stuff, ... but then to add the whole food thing.... I think it’s really hard just because of the social situations.... If you go to a family function ... there is all these brownies, cakes, pies, rolls, and stuff she wants.... And she can’t have them because they have gluten in them

and that's really hard because she already feels a little bit picked on [*laughs*] with the diabetes and then she has the celiac disease on top of that....

The mother of a 14-year-old daughter (diagnosed with T1DM at age three and CD at age 12) said about the second diagnosis,

It was really hard on her. She cried for a day because all of a sudden she couldn't eat this and she couldn't eat that and so I think in a lot of ways, it was more burdensome than even first dealing with the diabetes.

Another mother of two children, a 15-year-old son (diagnosed with T1DM at age two and one half and CD at age nine) and a 12-year-old daughter (diagnosed with both diseases around age five) said,

They both said if they could get rid of one disease, they'd like to get rid of celiac disease. They said they can deal with the shots and the insulin, 'cause they can eat whatever they want and just cover it with insulin. But it's sad to see them go to parties and stuff and not be able to eat with the other kids.... They get teased a lot and other kids say that their "food looks like dog food", and "why do they have to be so weird?"

One father of a six-year-old son with both diseases and a nine-year-old son with T1DM mentioned problems at school,

Kids are ruthless and just kind of ridicule and tease just when they see a pump attached, that's a target of jokes and a target of teasing, and a target of bullying.... It's crazy how mean people can be...." [*Mother chimes in about their oldest son's experience in the 2nd grade*], 'He said the kids were saying I was contagious and I shouldn't be around them.'

Another mother of a 12-year-old daughter (diagnosed with T1DM at age eight and CD at age nine) talked about her daughter's emotional frustration and negative reactions,

One time it was in the beginning and she was so angry and so mad that she took an insulin pen and drew up about 10 units and said ‘I’m going to give myself this many units and there is nothing you can do about it’.... She proceeded to give herself these 10 units and I knew to remain calm.... Then we ended up giving her some juice to cover for it, but we enrolled her in counseling, ... we needed to be all over this because it was definitely one of those moments where either she’s going to use this to threaten us to keep control or to gain control ... That was rough.”

The mother of a 19 year-old son (diagnosed with both diseases at age 14) told me of a crisis that happened to their family two years after her son was diagnosed. She said,

[My son] was diagnosed at 14, and in talking to other parents who have had type 1 diabetics and celiacs, there are a lot of acceptance issues and psychological problems that seem to come from being diagnosed as a teenager as opposed to say, if he was really young and had just lived with this all his life.... But the worst aspect of it was after about a year my son had some real acceptance problems with it, because by that time it wasn’t a novelty anymore and the reality was sinking in; he really does have to live with this for the rest of his life. And he could NOT accept it.... He refused to have anything to do with JDRF [*Juvenile Diabetes Research Foundation- support groups and activities*] at all. He said he didn’t want to go be around “freaks” and be reminded how sad life was.... There were very, very difficult situations that we went through.... When he was about 16½, ... he started talking along the lines of ‘I’m not going to live life this way.’ We of course got him counseling when we started to hear that kind of thing.... A month or two after we started cutting back on the counseling he made a very serious suicide attempt.... He was admitted to Wasatch Canyon’s for 10 days....

Support from Healthcare Providers

It is important for parents who care for children with chronic conditions to have access to and support from healthcare providers, who they can count on for on-going support and relevant up-to-date educational information. When asked about personal experiences with their child's healthcare provider, positive provider relationships were identified as being responsive to the parent's questions, willing to listen to what the parent has to say, having open and honest dialogues with the parent, seeing the child as a whole person (not just a diagnosis), having a personal relationship with the child, and being a patient advocate.

One mother of a school-age daughter (diagnosed with T1DM at age seven and CD at age nine) said about positive healthcare provider relationships, "I think just compassion and understanding that it's hard. And that they understand that we're doing the best we can...." The mother of a son diagnosed with CD at age nine and T1DM at age 12 spoke warmly about her son's healthcare providers:

Well, honestly... the biggest factor was how much they cared.... Our general doctor, who was not a specialist in any area, was the most helpful because when she didn't know she would lead us to somebody who did, and I think the sense of feeling like we're cared for in the medical community was more important.

Many parents discussed how helpful it was to have a knowledgeable dietician at the diabetes outpatient clinic who could provide them with current information and resources and help them understand the gluten-free diet and why it is important for children with CD. One mother of a six-year-old son (diagnosed with CD at age 17 months and T1DM at age two) said she needed to get information from a nutritionist or dietician about the celiac diet because "the doctors don't know... about the diet or anything, they're kind of clueless."

Some parents noted how valuable it was for them to have a “team” of providers, who communicated and worked together to ensure the best care for their child. One mother of six children, including a nine-year-old daughter fairly recently diagnosed with T1DM and CD stated,

Our pediatrician was very aware that the endocrinologist would provide the best treatment for her diabetes, and the gastroenterologist would provide the best recommendations for the celiac disease, and he would be the best overall care manager for her as an individual ... they were also all willing to work as a team together for her health.

Another parent of a 17-year-old daughter (diagnosed with T1DM at age nine and CD at age 10) talked about the team approach at the Primary Children’s Medical Center Diabetes Clinic in Salt Lake City, “At the diabetic clinic, they have a crowd of people who will come in and help you. The dieticians, the educators, they all know what everybody is doing ... they’re never conflicting with each other ... which is really nice.”

A few parents mentioned the importance of having nurses who were on-call resources and provided helpful information. One mother of four children with T1DM (including a daughter diagnosed at age 18 months with T1DM and CD at age eight) said, “I can call any time and the nurses are always really nice.... They don’t make me feel guilty like I’m not doing a good job and they’re just always there.” Another mother of a 12-year-old daughter diagnosed with “gluten and corn intolerance” at age 10 and T1DM at age 11 stated,

Having the on-call nurse available is probably the biggest resource.... I appreciate that they continue to re-educate me without treating me like I’m stupid.... They are always re-educating and answering questions and checking with you, and always teaching and re-teaching and I never feel belittled.

The mother of a nine-year-old daughter (diagnosed with both diseases at age eight) told of a valuable nursing experience she had when her daughter transitioned to an insulin pump and received one-on-one support from the Animus (pump manufacturer) nurse. She said,

I think I learned more through that process than any other, because so many of the intricacies of how her body behaves is uncertain, food, exercise, or just basal rates changes how that comes out in her blood sugar. So that was the most important thing educationally to me that we've done this whole time was working one-on-one with that nurse over the phone, explaining the cause and effect.

Community Support / Understanding

Several parents worried about public misconceptions regarding what it means to have T1DM and CD. Although most people are familiar with type 2 diabetes and the need to avoid sugar, they often misunderstand T1DM and believe the child can only eat things that are sugar-free. Also, because gluten-free foods have become part of a “fad diet” recently, people don't understand a strict gluten-free diet is essential for someone with CD.

One mother of a 14-year-old daughter (diagnosed with T1DM at age nine and CD at age 10) said,

Every once in a while you'll run into people, oh she has to have her 'special food'.... And they can be kind of rude about it.... Or if you go to restaurants and you say she's gluten-free so no spices on the meat and things like that, and they kind of look at you like you're just nuts and you're just making their life horrible.

Another mother of a daughter diagnosed with T1DM at age six and CD at age seven had the following to say,

Other people are not aware of it. They don't care about it. They don't understand the severity of it, like you go to a restaurant and if they don't speak English and are really clear about what is in this, 'I need to know specifically what's in this' and then they're like, 'it's fine, it's fine.' And then she comes home and is puking and has diarrhea all night. It has immediate effects on her.

Worrying that a child with both diseases is being properly cared for at school was another concern. Some parents reported positive experiences with teachers and school nurses being willing and interested in meeting the child's needs at school. However, other parents reported negative experiences; the teacher or school staff was either unaware of a problem or unwilling to work with parents in making necessary accommodations for the child during school.

One mother of four children with T1DM, including a 14-year-old daughter (diagnosed with T1DM at age 18 months and CD at age eight) expressed her concerns this way, "I worry a lot when they're at school.... and nobody will know what to do." The mother of a 12-year-old daughter (diagnosed with T1DM at age seven and CD at age eight) said, "As soon as we leave the house, that's when it gets a little tricky." Another mother who decided to home school her two sons (one age six with both diseases and the other age nine with T1DM) said,

People don't realize just taking a test, how much you have to test yourself before to know you are not too low.... So many think it's hard at school, especially when you don't have anybody willing to work with you.

A handful of parents were proactive in educating anyone and everyone willing to listen and learn in order to provide a community support system for their child with both diseases. They worked feverishly to educate friends, neighbors, and teachers about troubling symptoms to watch for and what could be done to help their child. For instance, one mother of a 10-year-old

daughter (diagnosed with T1DM at age seven and CD at age eight), concerned about hypoglycemia said,

I talked to her friends and just said, I can't be there like at lunchtime or recess so would you please be my eyes if [*my daughter*] repeats herself or acts weird or looks confused, would you go tell a teacher that she needs to check? Cause she'd be beyond the point of understanding if she got too low.

One family chose to stay within their school boundaries when they moved homes, because of their supportive community of the friends, neighbors, and school personnel. This particular mother with an eight-year-old daughter (diagnosed with T1DM at age five and CD at age seven) related her positive experiences this way,

We've heard of a lot of horror stories, basically, from other parents and families that... mostly with the diabetes part of it, that have had some trouble at their schools and people not quite understanding the magnitude of their disease and how important it is and things like that.... To have people that we trust caring for her was clearly our first priority so that's why we stayed here.

Another mother of a 19-year-old son (diagnosed with CD at age nine and T1DM at age 12) credited a school nurse for her son's positive elementary school experience,

When he was first diagnosed, the nurse there was really good. She brought in a video and showed the whole sixth grade, not just his class ... a video of what diabetes is, ... and then she had him check right there in front of everybody, poke himself and check his numbers so that they could see what he had to go through every day, several times a day to be able to survive.... They just all helped him through it. It was because of the school nurse that made that possible.

The adoptive grandmother of a 12-year-old granddaughter (diagnosed with T1DM and CD at age 11) said of their school nurse, “When she’s in school, we have the health nurse at school, she’s awesome. She’s there for us if [*my granddaughter*] needs anything, she knows right where she is and how to contact her.”

Several parents talked about the importance of their connections with community support groups and on-line resources, which provide them with information about gluten-free recipes and new gluten-free foods that are available. One parent talked about how her teenage daughter found a website where she could “go on and talk and chit chat with other kids that are diabetic,” which was very helpful to her.

Positive versus Negative Adaptation

The final theme, as observed by the researcher, highlights how positive versus negative experiences and adaptation of parents and children to life’s challenges plays a role in successful disease management, family functioning, and outlook for the future. Differences were noted between parents and children with a healthy outlook on the future and positive relationships with healthcare providers, especially soon after diagnosis when life was particularly stressful and difficult, compared to those with negative experiences soon after diagnosis who continued to view their challenges as nearly insurmountable. For example, one mother of a 12-year-old daughter (three years after diagnosis with both diseases) expressed the following positive attitude,

We’ve learned to appreciate life... daily, to live it up in a good way, and in her life... she just has an attitude toward life of, ‘Bring it on! I want to do it and I want to do it with gusto!’... She wants to enjoy her life and she’s not inhibited by, ‘Oh no, I’m nervous I can’t do that.’... It’s made her have a desire to live life to the fullest.

Another set of parents of a six-year-old son with both diseases and a nine-year-old son with T1DM try to not let the challenges of daily disease management stop them from doing the things they really want to do as a family, even though a lot of preparation has to be made ahead of time. The mother said,

We have done so many things with them; diabetes is not stopping us, and celiac is not stopping us either. We go hiking, and we do whatever. There is nothing we have said, 'Oh we cannot do that because we have celiac disease, or we cannot do that because we have diabetes.' We just find a way to do it.

The mother of a 16-year-old daughter shared her perception regarding her daughter's second diagnosis (CD),

It was a lifestyle change, but you know, it's a lifestyle change that you deal with it and you move on. And we try to always have that positive attitude, since she was young and had diabetes I would say, 'You know what? Everybody has challenges, some you can see some you cannot. Yours you cannot, but it's your challenge and you can fight and be strong and beat it or you can let it beat you.'

One mother shared an experience that positively impacted her teenage son soon after his T1DM diagnosis at age 12 (CD diagnosis was three years earlier at age nine),

And then while we were still at the hospital, they had... I don't even know what they're called, but it was a child that had diabetes, ... I think she was about 16 or 17 and then her mom that came in while we were still at the hospital. They delivered a backpack just full of different meters and different checkers and pokers, anything that had to do with diabetes. They came up and they delivered this backpack to *[my son]* and just talked to him. Just basically told him that 'Life isn't over, life changes a little bit, but there isn't

anything you can't do with diabetes.' And he just basically took that to heart and I mean he hasn't let it slow him down at all.

On the other hand, a completely different scenario happened with another teenage boy who was born the same year, but diagnosed with both diseases at age 14. It illustrates how negative early experiences often lead to difficulties with disease acceptance and trouble developing supportive relationships. His mother remembers feeling very overwhelmed and in denial following her son's diagnosis at age 14. She remembers having a hard time accepting the new reality herself, and recalled,

One thing that I remember from the first month or two is that it was very difficult to deal with the medical assistance.... For instance, in the hospital we were assured we'd never be alone with this, there was always going to be someone on-call at the hospital who would help us in this kind of thing. But our actual experience with that was that it could be very difficult to get help.... For instance, the first week I didn't know what was an emergency. 'Was it an emergency if his blood sugar was 193?' And the first time I called in with that, the person who answered was very short-tempered about it.... This is the first time we're ever dealing with this. Nobody ever said to me, ok this is when you panic, and this is when you don't. It was really, really discouraging and made us feel pretty alone with it.... Even though [*the children's hospital*] is really, really good, there is still a lot of little details you have to learn yourself, and some pretty impatient people to deal with at times. I think it would have been helpful if we had done it on our own at the hospital before coming home for the first time to do it on our own. Little things like that would have just made it easier, so that was kind of a problem that we had dealing with the medical community.... I think they cater more to younger kids.

Her son was also the young man who had a traumatic negative experience with peers during his first date to a school dance (within a year of his dual diagnosis). While his group was out to dinner, he pulled out his blood glucose tester and insulin administration kit just before dinner was served... the girls screamed and asked if he was “doing drugs?!” He didn’t know how to respond. Then he was treated like an outcast for the rest of that evening. His mother recalls the magnitude of the impact of that particular experience and how hard it was for him to move past it. At the age of 16 1/2, he tried to take his own life by administering 130 units of insulin to himself.

It’s important to remember a positive attitude, supportive and encouraging healthcare providers, and a team approach can really make a difference in the way the parent and child cope with the daily and long-term challenges of chronic disease management and will likely impact the degree of health related complications they experience early on in life.

Discussion and Implications for Practice

The purpose of this study was to investigate what it is like to raise a child with T1DM and CD. Previous research connecting both diseases focused on their genetic relationship and tendency to occur together in certain populations at risk. There are some studies examining parental experiences with T1DM alone, but no studies about the challenges and experiences of parents raising a child with CD or with both chronic diseases. Consequently, the major contribution of this study is to describe themes identified by parents related to parental challenges in managing and raising children with both diseases.

It is important to note that because T1DM and CD will never go away, constant vigilance, awareness, and attention by the parents and child over the course of the child’s life are necessary, 24 hours a day, seven days a week, and 365 days a year. Parents raising children with

T1DM alone have expressed feelings of being overwhelmed with disease management, so one can understand how the stress and sense of burden might be compounded if raising children with both chronic diseases. Both parents and children are exhausted with the reality of having to worry about the inconveniences required to stay healthy. Despite the challenges of raising a child with T1DM and CD, after a time of learning and adjusting, it does get easier and becomes a part of life; families do what has to be done, a new normal is established and they become less overwhelmed.

Health Complications

Parents worry a lot about how their success, or failure, in managing the diseases now might contribute to the development of future health problems. These feelings have also been reported in the literature. Specifically, Freeborn and colleagues (2013) found parents raising children with T1DM expressed concern about long-term complications of disease. In addition, parents raising children with both diseases seem to worry most about the well-documented negative health complications of T1DM, particularly blindness, kidney failure, and amputations, rather than the not as well understood or studied long-term complications of CD; although, a few parents did express concern about malnutrition, osteoporosis, infertility, and cancer. Olsson and colleagues (2009) identified the psychosocial challenges for teens with CD, but concerns for long-term health complications were not addressed.

Challenges of Daily Disease Management

It can be exhausting and challenging to always provide healthy, gluten-free meals, monitor blood glucose levels, calculate the carbohydrates in snacks and meals, and administer the appropriate insulin dosing for the carbs eaten. Many parents described the daily requirements for disease management as very stressful, requiring significant lifestyle adjustments

for the whole family. Freeborn and colleagues (2013) and Samasca and colleagues (2011) discovered parents raising children with T1DM felt overwhelmed with the responsibilities of managing the disease on a daily basis. Because eating is such an important part of life and both diseases are managed through a strict diet and structured meal-time routine, the day-to-day management can be overwhelming, particularly in the first several months following diagnosis.

Parents in the current study talked about the difficulties of going anywhere or traveling away from home, because of the amount of preparation, supplies, and food needed for management of both diseases. Most families did not let these challenges keep them from going places and doing what they wanted to do, after the initial period of adjustment. On the other hand, Freeborn and colleagues (2013) discovered parents expressed sadness about no longer taking family vacations. They found parents were fearful of letting the child go anywhere, which was also the case in the current research; parents stated apprehension about letting other people be responsible for the child's disease management.

Several parents worried about their child's needs being met at school, similar to the Freeborn et al. (2013) study. Therefore, nurse practitioners can be instrumental in advocating for student needs being met at school, by providing educational resources and a Diabetes Management Plan (DMMP), as referred to by Freeborn and colleagues (2013). A sample of a DMMP can be found at <http://www.diabetes.org/assets/pdfs/schools/dmmp-form.pdf>. This form can be modified to also include the CD management and gluten-free diet restrictions, as part of the Medical Directive Plan (MDP). There are several other online resources cited by Freeborn and colleagues for managing T1DM at school, including the American Diabetes Association (ADA) website at <http://www.diabetes.org/>. The Celiac Disease Foundation website at

<http://www.celiac.org/> has helpful information about CD, including diet and lifestyle tips, research, news updates, kids camp, conferences, and local support group contacts.

Time, Resources, and Expense of Managing Both Diseases

Diabetic supplies and insulin are expensive necessities for someone with T1DM. Cost of disease management can be a big concern for families. Monitoring blood glucose before snacks and meals, as well as calculating carbs and dosing the correct insulin is time-consuming, challenging, and requires careful attention. In addition, CD requires another aspect of inconvenience and expense. As mentioned by many parents, gluten-free food is often not readily available; it is expensive and requires much effort to produce at home (particularly breads and desserts). Consequently, nurse practitioners can assist parents in making sure the insulin, supplies, and other necessities for disease management are available to them on an on-going basis, with regular follow-up visits and prescription re-fills. These providers can also be aware of potential risk for poor disease management in children or adolescents of low-income families, or those without good health insurance coverage, who might be tempted to reuse supplies, limit blood testing, or not treat hyperglycemia with adequate insulin doses in order to limit cost. This was a concern mentioned by one parent whose daughter with T1DM and CD was getting ready to move away to college.

The Child's Emotional / Mental Health

Children diagnosed with both diseases at a young age seemed to have an easier time adjusting to the demands of disease management. They grow up with disease management as part of the daily "routine". However, several parents expressed concern about their child's emotional/mental health when they were "left out" at birthday parties or pizza parties at school because there was no gluten-free alternative. It is difficult for kids to feel "different" or

“singled-out” in a negative way around their peers. Several parents in the current research stated having CD was more emotionally challenging for their child, than having T1DM. This concern was not highlighted in the studies done previously on parents raising children with T1DM alone. On the other hand, Olsson and colleagues (2009) discovered teens with CD often feel sad, frustrated, alienated, angry, and left out in social gathering with their peers, due to the lack of availability of gluten-free foods at school, friends’ houses, restaurants, or other gathering places.

Indeed, it is important for nurse practitioners to be sensitive to the psychological and social challenges of children and adolescents living with CD. Parents and healthcare providers can be supportive by seeking resources and providing education regarding simple, readily available gluten-free foods (and recipes) for successful disease management, while encouraging a “normal” life.

Support from Healthcare Providers

Parents identified the importance of positive relationships with healthcare providers. The qualities they valued in their healthcare provider included being responsive to questions, willing to listen to what the parents have to say, adopting a “team approach”, having an open and honest dialogue with parents, being a patient advocate, and having a personal relationship with the child. Howe and colleagues (2012) identified supportive primary provider relationships assisted parents and families to successfully meet the challenges of living with T1DM, which included therapeutic “reassuring” relationship, expert advice with “anticipatory guidance,” engaging families as partners, and showing mutual respect and trust. These investigators also found parents appreciated having the providers undivided attention during clinic visits; they valued the clinician’s efforts to truly know and understand the child and the family, and respected providers

who engaged the families as partners in their child's care and helped them figure out how to live with diabetes.

It is important nurse practitioners assume an active role in helping parents of children with T1DM and CD effectively educate the children to take responsibility for their own disease management and offer simple suggestions for motivational rewards and effective consequences. Nurse practitioners can also help parents develop a positive outlook and coach the child to view their chronic disease as a part of life, but not something that has to stop them from doing anything and everything they want to do. As recommended by an endocrinologist, to the parents of a child diagnosed with T1DM at 17 months, "You are his coach and how you treat his disease is how he's going to view it. If you view it as a big deal, 'He's going to die,' that's how he's going to view it. If you view it as 'you've got diabetes, but that's ok, you can live your life,' then that's how he'll deal with it."

Nurse practitioners should be a source of education and support for these families, with patience, understanding, and encouragement, particularly in the challenging period of adjustment and acceptance following diagnosis.

Community Understanding / Support

A handful of parents had positive school support, involved extended family, and close friends who could relieve them from their ongoing burden of care for short intervals. However, many parents either didn't have extended family living close by or didn't have family who felt confident enough to help with disease management, without the parent's direct involvement; parents also didn't trust leaving their child in the care of anyone else, which was also noted by Freeborn and colleagues (2013). Most parents raising children with both diseases were frustrated with the lack of understanding in the community about what it means to have CD and the

importance of a gluten-free diet, as well as lack of understanding of the difference between T1DM and type 2 diabetes. In fact, one set of parents in this study chose to home school their six year-old son with T1DM and CD and nine year-old son with T1DM, due to the lack of positive support at school and their expressed concern about a safe school experience. Freeborn and colleagues (2013) found that “lack of understanding on the part of school personnel interferes with providing children with T1DM with a positive and safe school experience” (p. 13). Therefore, it is important for nurse practitioners to make a difference by taking an active role in offering families information and education they can provide to the child’s teacher, school staff, classmates, and grandparents.

Positive versus Negative Experiences / Adaptation

Parents and children with T1DM and CD face unique challenges as they adjust to the daily demands of disease management. Observed through the current qualitative descriptive design a positive outlook, successful adjustment to lifestyle changes required for disease management, healthy family relationships, and “living life to the fullest” were often connected to positive adaptation in the days and months following the initial diagnosis. Mednick and colleagues (2007) identified a strong inverse relationship between hope and distress in parents raising children with T1DM, where “hope” can actually be protective against parental “anxiety”. In the same study, a positive, hopeful outlook by parents was directly related to the physical health and social development of their children.

Those early experiences, whether positive or negative, can have a direct impact on the ability of the parent and child to make the necessary daily and long-term adjustments for successful disease management. Consequently, nurse practitioners can make a positive

difference by providing families with hope, showing patience, providing encouragement, and sharing knowledge.

Limitations and Directions for Future Research

The limitations to this study included a small sample with very little ethnic/cultural diversity, all living in the western United States. Families in this study had access to routine medical care and the financial means to provide the basic healthcare needs of their children with these chronic diseases. Future research needs to include a more diverse social, cultural/ethnic, and economic sample with few resources and limited access to medical care, so nurses can better understand the needs of more diverse populations.

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Table 1

Demographic Statistics

Variable	<i>M</i> or %	
Children in family	3.7 (1 to 9)	
Mothers		
Age	42	
Years education	14.6	
Hours employed/week	23.1	
Fathers		
Age	44	
Years education	14.0	
Hours employed/week	41.4	
Household income	34.6%	> \$75K
	34.6%	\$50K-75K
	23.1%	\$35K-50K
	7.7%	< \$25K
Child		
Age	12.6 (6 to 19)	
Age at diagnosis (DM)	6.7	
Age at diagnosis (CD)	8.8	
Female	80%	
Diagnosed with celiac first	11.5%	

Table 2

Description of Themes

Themes	Description
Health Complications	Vision loss, kidney failure, bowel cancer, cardiovascular disease, infertility, osteoporosis, and limb amputations.
Daily Disease Management	Frequent monitoring of blood glucose and carbohydrate intake, and diet restricted to gluten-free foods.
Time, Resources, and Expense	<u>Medical</u> - cost of insulin and diabetic supplies and time spent at pharmacy and doctor visits. <u>Diet</u> - limited availability and costliness of gluten-free foods and time spent in meal preparation.
Child's Emotional / Mental Health	Feelings of isolation, being "different" from peers, being teased and misunderstood.
Healthcare Professionals	Valued: a team approach, responsive to questions, willing to listen, open and honest dialogue, personal relationship with child, and patient advocate.
Community Support	Public and extended family misconceptions and lack of understanding about T1DM and CD including; children with T1DM can eat sugar and children with CD need a strict gluten-free diet. Concerns about proper care during school.
Positive vs. Negative Adaptation	<u>Positive</u> - regular doctor visits, good health habits, greater sense of control, active kids, living a "full-life," more family vacations. <u>Negative</u> - parents overwhelmed, poor disease management, increased sense of burden, kids more depressed, less participation in extracurricular activities, and limited family vacations.

Appendix A

Interview Questions

1. *Warm-up question:*

Tell me a little about your family.

2. Talk to me about your experiences raising a child with type 1 diabetes and celiac disease.

(Follow-up questions, if not answered)

- a. Which disease was your child diagnosed with first? T1DM or CD?
 - b. How did your feelings or sense of burden differ when your child was diagnosed with the second chronic disease?
 - c. How did you learn about each disease?
 - d. What lead up to you finding out that your child had a chronic disease? (What led you to seek medical advice?)
2. Talk to me about your experiences with your child's healthcare provider(s).

(Prompts, as needed)

- a. Who or what was most helpful to you in gaining knowledge and understanding about your child's illnesses?
- b. Have most of your contacts in the Healthcare system been with a Primary Care Provider or a Specialist, in meeting the health needs of your child?
- c. What kind of support or information have you received from healthcare professionals in terms of caring for your child?
- d. What would be most helpful in your relationship with doctors and nurses that care for your child?

3. What are your primary concerns and biggest challenges regarding your child with diabetes and celiac disease?
4. Tell me about the kind of help you receive on a daily basis.
5. How involved are other family members in managing your child's diseases?
6. How have celiac disease and type 1 diabetes affected other family members?
(prompts- siblings, parents, extended family, etc)
7. What concerns do you have about your child's independence, as he/she grows older?
(Follow up, if not answered)
 - a. At what age do you expect your child to be independent in meeting most of his/her own physical (health related) needs?
8. Is there anything else you would like to tell me?

Appendix B

Demographic Questionnaire

Family Information Questionnaire – T1DM/CD

ID# _____

- 1. Today's Date _____
- 2. Family ethnicity _____
- 3. How/where family was recruited _____
- 4. Ethnicity of child with disability/chronic condition (if different from family) _____
- 5. Child with T1DM/CD birth date _____ Gender _____
(Age at diagnosis: T1DM _____ CD _____)

6. First names of all other children in your family.

Name	Gender	Birth date (M/D/Y)	Health concerns (if any)
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

7. Family composition: (circle one)

- a. Two Parent Family
- b. Single Parent Family
- c. Step Parent Family
- d. Other Family Type _____
- e. Other adults besides parent living at home? Y / N
- f. If yes, who? _____

8. Age of parents: _____ Father _____ Mother

9. How many years of education has husband completed? _____ years

10. How many years of education has wife completed? _____ years
11. If husband has been employed outside of the home during this past year, has the employment generally been full time or part time? _____
12. _____ Number of hours husband works per week.
13. If wife has been employed outside of the home during this past year, has the employment generally been full time or part time? _____
14. _____ Number of hours wife works per week.
15. _____ Husband's religious preference.
16. _____ Wife's religious preference
17. What is your total family income?
 - a. Under \$7,000
 - b. \$7,000-\$15,000
 - c. \$15,001-\$25,000
 - d. \$25,001-\$35,000
 - e. \$35,001-\$50,000
 - f. \$50,001-\$75,000
 - g. \$75,000-\$100,000
 - h. Over \$100,000