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Understanding the Perspective of Adolescent Siblings of Children with Down Syndrome Who Have Multiple Health Problems

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UNDERSTANDING THE PERSPECTIVES OF ADOLESCENT SIBLINGS OF CHILDREN
WITH DOWN SYNDROME WHO HAVE MULTIPLE HEALTH PROBLEMS

by

Carol Ann Graff

A thesis submitted to the faculty of

Brigham Young University

in partial fulfillment of the requirement for the degree of

Master of Science

College of Nursing

Brigham Young University

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BRIGHAM YOUNG UNIVERSITY

SIGNATURE PAGE

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ABSTRACT

UNDERSTANDING THE PERSPECTIVES OF ADOLESCENT SIBLINGS OF CHILDREN WITH DOWN SYNDROME WHO HAVE MULTIPLE HEALTH PROBLEMS

Carol Ann Graff

College of Nursing

Masters of Science

The purpose of this qualitative descriptive study was to obtain information from adolescent siblings of children with Down syndrome (CWDS) regarding their perceptions of living with a child who has Down syndrome (DS). Twenty-three adolescents between 12 and 19 years of age who lived with a child who had DS and additional health problems including cardiac, endocrine, gastrointestinal, hematological, neurological, and behavioral conditions were interviewed individually. After examining the tape recorded interviews, major themes revealed both positive and negative aspects of living with a child with DS who has major health problems. However, overall the adolescents reflected more positive experiences than negative experiences. In addition, most adolescents interviewed said they would not change anything about their experience. One interesting finding was that most participants did not believe the child with DS would ever live independently, perhaps because of the additional health problems these CWDS have. Information gained from this study provides information for nurses and families to help better understand adolescent sibling perceptions about living with a CWDS so more appropriate and individualized nursing interventions can be provided for siblings and their families. This

information can assist nurses in supporting similar families gain better coping skills, learn more about the impact of DS on families, and provide information on stress management and nursing interventions to support family growth and development especially for adolescents who have the added responsibility of caring for and living with a CWDS.

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Chapter 1

Introduction

Down syndrome (DS), a chromosomal abnormality, occurring in one out of 733 births, affects approximately 400,000 people in the United States (National Down Syndrome Society [NDSS], 2009b). DS accounts for roughly one third of moderate to severe cases of intellectual disability but the severity of intellectual disability a child with DS (CWDS) has may vary (Ferri, 2009). However, most CWDS have appropriate social skills and are good visual learners (Cooley, 2004). On the other hand, many CWDS also have a number of health issues including cardiac defects, hematological disorders, intestinal malformations, orthopedic problems, thyroid disorders, and visual, hearing, and language impairments (Genetic Science Learning Center, 2009). Nevertheless, many children with DS and these health problems are living longer today than in the past because of advances in medical technology. They are also living at home with their families more than in the past, and their health problems affect their care and the family members (Ferri; NDSS, 2009c; Potts & Mandleco, 2007).

Raising a CWDS affects many aspects of family life. Specifically, it not only affects the wellbeing of the person with DS but also the wellbeing of all family members, including siblings. In fact, it is becoming evident today that sibling wellbeing may be profoundly affected by the experience of living in a family raising a child with a disability or chronic condition such as DS due to the care these children require (Mandleco, In Press; Van Riper 2000).

Although there has been some research on siblings of CWDS, most data have relied on parent perspectives rather than firsthand information from siblings themselves. In addition, there is very little data showing the effects on siblings of living with a CWDS when the sibling is an

adolescent and when the CWDS has serious health problems such as cardiac anomalies, endocrine disorders, gastrointestinal disorders, neurological developmental disorders, or respiratory disorders. Indeed, further research is needed to fill the gap and understand the perceptions adolescent siblings of CWDS have when the CWDS has other serious health problems. Therefore, the purpose of this study was to obtain information from adolescent siblings of a CWDS who has additional health problems involving the cardiac, endocrine, gastrointestinal, hematological, neurological, or respiratory system regarding their perceptions of living with the CWDS so more appropriate nursing interventions can be developed and implemented for these siblings and their families to support family growth and development, help gain better coping skills, and learn more about the impact of DS on families.

Literature Review

Down Syndrome

Down syndrome, also known as trisomy 21, describes the presence of three copies of chromosome 21 instead of a normal pair of chromosomes. Therefore, infants born with DS have 47 chromosomes instead of the normal 46 (23 pairs) caused by an error in cell division occurring following conception. There are three types of DS. Trisomy 21 (nondisjunction) occurs 95% of the time; 4% of children with DS have translocation and 1% have mosaicism. Nondisjunction occurs when the 21st chromosome fails to separate properly during cell division, leaving an imbalance of chromosomes. Translocation occurs when part of the 21st chromosome breaks off during cell division and attaches to another chromosome. Mosaicism occurs when nondisjunction of chromosome 21 occurs in one but not all of the initial cell divisions so there is a mixture of two types of cells on the chromosome. Consequently, individuals with mosaicism may have

fewer characteristics of DS, than those with nondisjunction or translocation (NDSS, 2009b, 2009c).

Down syndrome occurs in 1 out of 733 births (13.65 per 10,000 births). In 2006, Utah reported a rate of DS of 1 in 665 births (Utah Department of Health, 2008). Today there are approximately 400,000 people with DS in the United States. DS is also the most frequently occurring chromosomal abnormality seen in all races and economic levels (NDSS, 2009b). Maternal age is the primary risk factor for the occurrence of DS, but 80% of CWDS are born to women under 35 years of age (NDSS; Utah Department of Health).

Intellectual disability accompanies DS. The average IQ level ranges from mild to moderate with fewer than 10% of CWDS having severe mental retardation (NDSS, 2009b). However, most CWDS have good social skills and are good visual learners. Thirty years ago, the average life expectancy of CWDS was 25 years. Today with improved health care and social support, people with DS are living longer (NDSS). In fact, the average life expectancy for people with DS is now 60 years old (NDSS). Besides living longer, CWDS also demonstrate improved academic and life achievements over time (Hodapp, 2007). Therefore, when parents are planning for the future of their CWDS, most expect a sibling to provide care when parents die or are incapacitated (Cuskelly & Gunn, 2003). However, for many young adults with DS, leaving home and establishing a separate adult life is a life long dream and if the transition is planned well, many adults with DS are able to live independently with appropriate support and supervision (Robison, Krauss, & Seltzer, 2009).

Several defects affecting a number of body systems are often seen in CWDS. Congenital heart defects are the most common and approximately 50% of infants with DS will have a heart

defect (Cooley 2004; NDSS, 2009b; Utah Department of Health, 2008). CWDS are also at increased risk for developing a variety of other health problems affecting the gastrointestinal, hematological, neurological, respiratory, or sensory systems including intestinal malformations such as Hirshprung's disease or blockages, celiac disease, childhood leukemia, asthma, chronic infections, many types of visual and hearing impairments, and Alzheimer's disease (Cooley; Genetic Science Learning Center, 2009; NDSS). Even though the frequency of attention deficit hyperactivity disorder (ADHD) in CWDS is not known, it is a commonly diagnosed childhood problem in these children as well (NDSS, 2009a). Finally, almost 30% of CWDS develop thyroid disease in their lifetime (Genetic Science; NDSS, 2009b; 2009c).

Adolescence

Adolescence is the psychological and emotional transition from childhood to adulthood. It is a time of tremendous growth and development, when specific milestones need to be reached such as feeling a sense of belonging, acquiring and mastering skills important to a valued group, developing a sense of self-worth, developing at least one reliable relationship with another, and demonstrating cognitive potential (Dunn & Fisher, 2009). During adolescence, the prefrontal cortex, which controls abstract thinking, reasoning, judgment, self-discipline, ethical behavior, personality, and emotions, is experiencing rapid growth and reaches maturity some time during the twenties. The changes in the quality of adolescent thinking along with physical and emotional changes occur during this period, result in a more self-centered view of the world (Dunn & Fisher). Social relationships also emerge during adolescence, and are the result of increased interaction with peers outside of the family environment. In addition, emotional distance and conflict between parents and siblings commonly increase (Coch, Fischer, &

Dawson, 2007). In fact, Noller (2005) found evidence suggesting sibling relationships affect adolescents' cognitive, social, and emotional development, which in turn also affects the relationship adolescents may have with peers.

Being a Sibling

The sibling relationship may be the longest, most significant, dynamic, and influential relationship brothers and sisters have. This is because siblings spend more time together in childhood, and their life spans overlap more with each other than with their parents (Cox, et al., 2003; Whiteman & Christiansen, 2008). In addition, siblings provide support, guidance, companionship, and share intense emotional experiences with one another (Noller, 2005). In fact, sibling relationships also endure regardless of circumstances and siblings seem to play deeper roles in each other's development as time goes on (Mandleco, Olsen, Dyches, & Marshall, 2003).

Sibling roles and relationships interweave with families; indirectly through interactions with parents, and directly with siblings (Schutermann, 2007). However, sibling relationships may be different when there is a child who has a disability in the home. This is because, besides caretaking, siblings may serve as significant companions and friends for children with disabilities. They may also help socialize children with disabilities to others outside the home (Floyd, Purcell, Richardson, & Kupersmidt, 2009). However, the research regarding the effect on siblings of living with children who have a disability has yielded mixed results; research has shown negative, positive, or little effect on siblings who are living with a child who has a disability.

Negative effects on siblings. Some research shows living with a child who has a disability such as DS or other disabilities is stressful and causes difficulties for siblings (Baumann, Dyches, & Braddick, 2005; Van Riper, 2000; 2007). One reason for these difficulties is parents of children with disabilities have increased demands and devote much of their time to child care and educational activities for the child with disabilities. Consequently, the needs of the child take priority over meeting the needs of other family members, including siblings, which may cause them to experience a diminished self-concept (Van Riper, 2000, Mandleco, et al., 2003). In addition, how siblings cope and adapt to the experience of living with a CWDS or other disabilities may be impacted by the loss of normal sibling relationships (Mandleco, et al.). Therefore, needs of the child with disabilities may take priority over needs of typically developing children due to a pile-up of demands within the family (Van Riper, 2000; 2007). Consequently, many siblings of children with disabilities such as DS assume additional care giving roles that are normally assumed by parents; most often, these are older sisters (Skotko & Levine, 2006; Waite-Jones & Madill, 2008). However, siblings of CWDS may be impacted differently. For example, Cuskelly & Gunn (2003) found a negative association between avoidance and activities that involved sibling care giving in families raising a CWDS. Whereas, Dyke, Mulroy, and Leonard, (2008), found some siblings of CWDS felt there was increased burden and responsibility related to assisting the needs of the child.

Little effect on siblings. Other research indicates little or minimal effect on siblings when families raise a child with disabilities. For example, some researchers discovered very little difference in school-aged siblings of children with disabilities and school aged siblings of typically developing children in relation to self-concept, social and self-competence, acceptance,

and empathy (Cuskelly & Gunn, 2003; Mandleco, In Press). In addition, Cuskelly and Gunn (2003; 2006) found siblings of CWDS did not differ from siblings of typically developing children concerning many aspects of their sibling relationships, in interactions with friends, academic performance, behavior, and competence.

More positive effects on siblings. However, other research shows siblings of CWDS are impacted positively rather than unfavorably by the situation (Kaminsky & Dewey, 2001; Skotko & Levine, 2006; Van Riper, 2007). For example, when brothers and sisters of CWDS in Australia matched by gender, age and birth order were compared to siblings living with a typically developing child, the siblings of CWDS reported more empathy and positive interactions in their sibling relationships than siblings of typically developing children (Skotko & Levine 2006). In addition, Kaminsky and Dewey (2001) found siblings of CWDS have kinder and more positive interactions than siblings of typically developing children. Indeed, for many siblings, the experience of living in a family raising a CWDS is a positive, growth-producing experience. A hallmark finding known as the “Down syndrome advantage” may explain this situation:

Many studies find that, compared to families of children with other disability conditions, families of children with Down syndrome cope better. Families seem to be warmer and more harmonious, and most studies find that families generally cope better when they include a person with Down syndrome” (Hodapp, 2007, p.280).

Current research has not identified exact causes regarding the Down syndrome advantage, but it may be related to the typical upbeat and social personality of CWDS (Hodapp, 2007).

Furthermore, Cuskelly and Gunn (2003) found trends toward more positive interactions between

the child and sibling if the child had DS when compared to siblings of children with other disabilities. Finally, Cuskelly and Gunn (2006) discovered siblings of CWDS showed increased levels of empathy, kindness, and appreciation toward the CWDS, and Dyke and colleagues (2008) found positive effects for siblings of CWDS were related to increased maturity compared to their peers, better tolerance and understanding of differences, added compassion, and better appreciation of their own health and abilities.

The results of these studies show differences in the effect of living with a CWDS compared to children with other disabilities. In addition, researchers recognize the importance of conducting further research to understand the experience of siblings of CWDS.

Methodology

Study Design

A descriptive qualitative design was used. The question asked was, what it is like for an adolescent to grow up with a CWDS who has additional health problems.

Participants

Twenty-three adolescents who were all older siblings and living at home with the CWDS, ages 12-19 (mean age 16 years; SD 2.15) 11 of whom were brothers and 12 who were sisters took part in the study. The participants and their parents (father's mean age 48.55; SD 5.64; mother's mean age 46; SD 4.54) who had participated in the Institutional Review Board (IRB) approved Families Adapting to Disabilities/Chronic Conditions Project were contacted and re-consented/re-assented since this was an additional arm of the study. The siblings came from 11

two parent families (mean number of children = 5.82; SD 2.6) who earned more than \$50,000 per year. All fathers worked full-time and three of the mothers worked either full- or part-time. Fathers had an average of 16.3 years of education (SD 4.59) and mothers had an average of 12.73 years of education (SD 5.04). The mean age of the CWDS was 12 years (SD 2.53), with a mean average of 4.18 additional health problems. Refer to table 1 for a description of the health problems of the children with DS. Even though some of the health problems (i.e. the congenital cardiac and gastrointestinal anomalies) may have been repaired, these children still have health problems that affect their quality of life.

TABLE I. Health problems of CWDS

Category: 11 CWDS	<i>Frequency</i>	<i>Percentage</i>
<i>Neurologic developmental disorders including: ADHD</i>	2	18%
<i>Congenital heart defect including: atrial septal defect (ASD), ventricular septal defect (VSD), patent ductus arteriosus (PDA)</i>	7	64%
<i>Cardiac disorders including: congestive heart failure, pulmonary hypertension, Wolf Parkinson disease</i>	4	36%
<i>Chronic ear infection</i>	2	18%
<i>Psychiatric disorders including: depression/anxiety</i>	1	9%
<i>Gastrointestinal disorders including: celiac disease, duodenal atresia, duodenal stenosis, Hirshsprung's disease, rectal fissures, reflux</i>	7	64%
<i>Endocrine disorders including: diabetes, Hashimoto thyroiditis, hypothyroidism</i>	5	45%
<i>Eye Problems including: cataracts, visual loss</i>	2	18%
<i>Hearing loss</i>	2	18%
<i>Hemolytic disorders including: leukemia</i>	1	9%
<i>Neurological disorders including:</i>		

<i>ocular migraines</i>	<i>1</i>	<i>9%</i>
<i>Orthopedic problems including: arthritis, jaw reconstruction, joint and bone surgery</i>	<i>2</i>	<i>18%</i>
<i>Respiratory disorders including: asthma, tracheal airway collapse, sleep apnea</i>	<i>4</i>	<i>36%</i>

Procedures/Setting

After receiving re-assent and parent re-consent, the primary investigator made appointments to interview the adolescent siblings in a quiet place in their homes to ask them about their perceptions of living with the CWDS who had other serious health problems. Data sources included tape-recorded one-on-one interviews following a guide (see Appendix A) and field notes. Each adolescent received a \$10.00 gift card in appreciation for the time spent in the interview.

Measures

Parents completed a family demographics form and The Child with Special Needs Description (American Association on Mental Retardation; 1992) asking information about the kind of care the CWDS required (See Appendices B and C). However, only two questions were used to help determine each child’s other health problems. The questions asked were: please list any physical health related conditions your child has, and please list any psychological or emotional difficulties (e.g., mental illness) your child experiences. These instruments have been used in previous research.

Qualitative Analysis

The primary investigator and a research assistant transcribed the audio-taped interviews verbatim, and then entered them into NVIVO for data storage and management. The transcribed

interviews were then examined by the primary investigator and two additional researchers for patterns and themes according to qualitative methodology (Polit & Beck, 2008). The themes were then sorted into categories according to each question so themes for each question could be compared across participants; direct quotes that best reflected the themes were then chosen. All identifying data were removed at the time of transcription and audio tapes were destroyed after transcription. To assure trustworthiness, credibility was established by prolonged engagement with participants and peer debriefing. Three coders reviewed the coded interviews and discussed the difference in coding until consensus was reached, and an investigator who had not participated in the analysis reviewed the findings to ensure that themes, descriptions, and quotations were clear and representative (Polit & Beck, 2008).

Results

Learning about the Disability

The first question asked was, "Tell me how your family members learned about (the kind of disability the child has)". Thirteen of the 23 adolescents could not remember how they initially learned about DS, since most were very young. In fact, seven said they had just grown up with the CWDS. For example, a 12-year-old female of a CWDS who had a congenital heart defect repaired and also had a hemolytic disorder stated, "I've always known he had it". Fifteen adolescents learned about the child's DS through their parents or from the hospital staff. Another 16-year-old male of a CWDS who has a neurologic developmental disorder and migraines stated, "My parents came down and I think explained it a little to us and just said, "She's going to be a little different". Four siblings learned about DS by doing research. One 16-year-old brother of a CWDS who had a hemolytic disorder and repaired congenital heart defect stated, "I just

remember looking up in the dictionary to see what ‘they were’ (CWDS) and it was hard”.

Another 18-year-old brother of a CWDS whose congenital heart defect was repaired, but now has cardiac, gastrointestinal, and speech problems stated, “I didn’t know what was going to happen, so I started doing research...and found out what it is”.

What it is like growing up with CWDS

Analysis of three questions, (Tell what it was like growing up with CWDS; What is easy about living with CWDS; What is difficult about living with CWDS) yielded similar results related to positive/negative, easy/difficult, and both positive and negative effects. A discussion of each follows.

Positive effects. Interestingly, when asked what it is like growing up with a CWDS, the vast majority of participants (21/23) found the experience very positive. For example, one 16-year-old sister of a CWDS who has a congenital heart defect, endocrine, and gastrointestinal problems said, “He’s taught me acceptance and responsibility so I’ve...learned a lot really...and it’s been amazing. It’s the biggest blessing I’ve ever had”. Another 14-year-old sister of a CWDS with a repaired congenital heart defect, gastrointestinal abnormalities, pulmonary problems, and hearing loss stated, “I think...I actually, I love it... it’s a lot of fun ‘cause she’s just...so happy all the time and...really fun to be around”. Yet another 19-year-old brother of a CWDS who has a neurologic developmental disorder and migraines expressed, “It’s neat to see the world through her eyes because... she has a different perspective...(it’d) be hard to see if I wasn’t [her] brother”. In addition, seven participants thought living with a CWDS was fun. One 15-year-old brother of a CWDS whose congenital heart defect was repaired, and now has several neurologic developmental disorders, respiratory, and gastrointestinal problems said, “It is fun to teach him

new stuff. I am teaching him how to play the Wii. He has actually got pretty good in the last couple months. He can kill me”. Another 18-year-old brother living with a CWDS who has respiratory problems responded, “She’s always happy and that tends to rub off on people”.

Several adolescents mentioned the impact the CWDS had on their family as a whole was positive. One 18-year-old brother of CWDS with respiratory problems stated,

When she is sick it affects all of us and you know, we’re all stressed when [my sister’s] sick and so I think we all try to work together to get her better as soon as possible and just to help her out. It makes us work harder... It makes us think about other people... it makes us a little more...compassionate and caring towards others.

Finally, a 17-year-old brother living with a CWDS who had cardiac and gastrointestinal surgery along with orthopedic, pulmonary, and hearing problems said, “I think it’s actually been a big family builder ‘cause it gives us a cause for us all to...bond together better and get to know each other better”.

Negative effects. Nineteen of the 23 respondents mentioned the challenges or negative effects associated with living with a CWDS. The experiences have affected the adolescents in several different ways; it was frustrating, worrisome, and they had to assume more responsibility for family obligations. For example, four siblings felt it was trying and frustrating to live with a CWDS. In fact, one 16-year-old sister who was living with a CWDS who had endocrine, gastrointestinal, and past cardiac defects responded, “It’s trying, it’s really frustrating...because you just want him to be able to do things as quick and understand things as easy as a normal child”. One 16-year-old brother of a CWDS who has gastrointestinal, respiratory, and neurologic

developmental disorders expressed, “It causes me to sometimes get really angry at him...even though he can’t control it...it is still...a pain”. In addition, ten siblings said they worry and were scared. One 13-year-old sister, living with a CWDS who had cardiac and gastrointestinal surgery, and also struggles with hearing, orthopedic, and respiratory problems responded,

Her health has always been a little iffy; we’re always more worried about when she’s sick. Then maybe if I got sick, they probably wouldn’t be as worried because I’m healthier, I guess. It makes me scared...when she just gets sick, I always say an extra prayer because I am...a person that gets scared.

Easy. Nineteen participants thought the easiest thing about living with the CWDS was his/her personality. They also said the child was fun, good tempered, loving, and forgiving. Several siblings responded that it is easy to spend time with and talk to the CWDS. One 19-year-old sister of a CWDS who has respiratory, gastrointestinal, and neurologic developmental disorders said, “He is always there to hang out with. He always wants to come and do stuff with me”. Another 16-year-old sister of a CWDS whose congenital heart defect was repaired and had a hemolytic disorder stated, “He just makes everything fun and funny...he laughs and his laugh is contagious”.

Difficult. On the other hand, behavior, personality, and time management of the CWDS were some of the difficulties mentioned. Fourteen participants felt the CWDS was demanding, destructive, and did not listen very well. A 17-year-old brother who was living with a CWDS who has a repaired cardiac defect, endocrine problems, and chronic ear infections stated, “She doesn’t listen very well and she’s very stubborn and she gets mad easily”. Another 12-year-old

sister of a CWDS whose cardiac defect was repaired and now has endocrine, respiratory, and gastrointestinal problems responded, “She hits herself or she hits her head on the floor.

She...yells... she just has a lot of problems”. Yet another 16-year-old brother of a CWDS who has a repaired heart defect, respiratory, skin, hearing, and gastrointestinal problems said, “When I have to do homework sometimes he can really be nagging on me the entire time I’m doing the homework because he wants me to go and do something else”. Stubbornness was another perceived difficulty. For example, a 16-year-old sister of a CWDS who has endocrine and gastrointestinal problems replied, “He likes to do things in his own time, and he’s very stubborn”.

Both positive and negative effects. Several siblings saw both positive and negative aspects of the situation. For example, one 18-year-old brother of a CWDS with respiratory problems responded, “Its fun and sometimes not fun at the same time. She’s a cute girl...she’s awesome but sometimes really stubborn and doesn’t like to listen”. In addition, one 18-year-old sister of a CWDS who has endocrine problems and had gastrointestinal, eye, and orthopedic surgeries said,

Oh, gosh, it’s so much fun. She can be kind of crazy at times, and it can be kind of hard watching other sisters that are around our same age and see how functional that the little sisters and how much...they do with each other. It’s kind of hard when I see [child’s name] and I know we’re never going to have those kinds of things, but I feel like I know her better than other sisters, its great. It’s really hard sometimes and...sometimes I really wish she was normal. But overall I don’t think I would ever change who she is or what she has become...I

know that she's supposed to be Down's and supposed to have these trials to help me and...my family, it's not necessarily her trial, it's almost ours...because of her, we are who we are, both spiritually and physically.

The Impact on Family, Parents, and Self

Three questions asked. "Tell me how this health condition has affected your parents; Tell me how this health condition has affected your family; Tell me how this health condition has affected you". These questions dealt with the impact of the CWDS on the entire family, especially since the child had a serious health problem in addition to the DS. In response to this question, themes identified related to the parents, the family as a whole, and the sibling. Each theme will be discussed in the following paragraphs, and as noted, the CWDS had a serious health problem often was mentioned.

Impact on parents. Fifteen of 23 respondents commented that their parents experienced additional stress involving their finances, time management issues, and personal relationships. One 18-year-old brother of a CWDS who has cardiac and gastrointestinal problems responded, "My mom spends every day watching out for him, working with him, trying to find people to work with him that will help him improve his understanding and his mental and physical needs and she's always working". Another 17-year-old brother of a CWDS who has a heart defect and endocrine problems stated, "My dad's taken time off of work a lot to go to the doctor with her. I'm sure it stresses my mom out every time she goes to the doctor". In addition, half of the participants mentioned the positive and negative aspects on their parents raising a CWDS. One 15-year-old male living with a CWDS who had cardiac surgery and a hemolytic disorder expressed, "It was probably a growing experience for them and it's probably good and bad at the

same time because all the money that they spend...they've learned a lot from him". A 19-year-old brother of a CWDS who has neurologic developmental disorders commented,

I think it causes a lot of stress, and they're very patient with her and they take care of her the best they can. I think in some ways it's put a stress on their marriage but at the same time it really reinforces it, 'cause there's no way that they could do it alone. But I think they've learned to work together a lot...more.

Impact on family. The siblings mentioned both positive and negative effects on the family. One 17-year-old brother of a CWDS, who has cardiac, gastrointestinal, respiratory and orthopedic problems responded, "I think it's actually been a big family builder...it gives us a cause ...to kind of bond together and get to know each other better". Another 16-year-old brother of CWDS who has cardiac, respiratory, endocrine, and neurologic developmental disorders stated, "we usually all take turns babysitting him...if we just forget one pill it makes our job really harder...Finally one 13-year-old sister of a CWDS with neurological developmental disorder replied, "We can't go out as much...we all get frustrated and it's hard to deal with...Sometimes...we come back and everyone's frustrated and you have to deal with her (CWDS)...You have to have new patience and everyone is worn out".

Impact on siblings. The siblings also mentioned the impact on them personally. Awareness and added responsibility affected respondents but seemed more negative than positive. Responsibilities included shopping, babysitting, caring for, watching out for, and giving medications and injections to the CWDS. For example, one 14-year-old sister of a CWDS who struggles with cardiac, gastrointestinal, respiratory, and endocrine problems stated, "I'm really

careful around her. I'll make sure she's always alright and it's really nerve racking... because she's always running around...outside". Another 18-year-old brother of a CWDS who has cardiac and gastrointestinal problems as well as speech difficulties stated, "We just have to always be aware of what's going on. He has to have multiple medicines every morning and night which sometimes can get frustrating, if you don't get it to him then he can get really sick". Finally, an 18 year-old-female sibling of a CWDS who has endocrine problems and had gastrointestinal, eye and orthopedic surgery responded, "I had to learn how to give shots and test blood sugars... that was really scary for me at the beginning. I didn't want to give shots and I felt I was hurting her... It was really hard, but I've mastered it now".

On the other hand, seven participants felt that living with a CWDS has made them better. For example, one 16-year-old sister of a CWDS who has a heart defect, gastrointestinal, and endocrine problems stated, "In the end it's teaching a lot more than I could ever ask for...it's something I would never want to change. I'd always have him the way he is". In addition, a 16-year-old sister whose sibling had cardiac surgery and a hemolytic disorder stated, "It's amazing for me; I have my own health problems, and just to see him be able to go through it and to still have... be positive about everything. It's just an inspiration to me. I want to be able to be like him". Finally, one 18 year-old-brother of a CWDS with respiratory problems responded, "I am a lot more patient with people and a lot more humble. I keep thinking about what kind of person I'd be. I'd probably be one of the biggest jerks if I didn't have [child's name]. It's made me very considerate of other people".

If You Could Change Anything

The adolescents were asked, “If you could change anything about growing up with CWDS what would it be?” The most common responses were the ability to communicate better with the CWDS, as well as changing some of the CWDS’s negative behaviors. In addition, several participants expressed the desire to change themselves. However, most adolescents felt they would not change anything at all.

Six adolescents mentioned the difficulty they had communicating with the CWDS as an area they wished could be changed. Often because of this, the participants needed to develop different communication patterns and skills such as acting out what the sibling was trying to say, like in a game of charades. For example, one 16-year-old brother of a CWDS who struggles with psychiatric, respiratory and neurologic developmental disorders voiced a concern related to communication including figuring out how to improve the child’s understanding of what was being said: “I wish you could talk to him better...when you ask him questions...he doesn’t really know how to respond correctly, and kind of leads you in a circle. I just wish he understood what we were asking him sometimes”. Another 13-year-old-sister of a CWDS who has cardiac, respiratory, gastrointestinal, and orthopedic problems stated, “Probably making it so that [child’s name] could talk to us and tell us what she wanted and what she didn’t want”. An 18-year-old brother of a CWDS who has cardiac, gastrointestinal, and speech difficulties responded, “I wish I could understand him more, because he’s a little bit harder to understand than most Down syndrome’s ... he slurs his words a lot. It would be nice to understand him, so I could easily tell what he’s talking about and what he wants”.

On the other hand, five adolescents mentioned they wished the CWDS's behavior could be changed. For example, one 14-year-old sister of a CWDS who has cardiac, gastrointestinal, respiratory and orthopedic said,

If I could change anything, I think I'd change how she's like really sassy in a way... She doesn't really like to do what you tell her to, she would rather... do what she wants, and usually that's not a problem unless you want her to come to you...or get out of the area when she locks herself in.

Another 12-year-old sister from the same family responded, "Well, to maybe...make it so she is easier to handle... when you try to pick her up she yells... When you pick her up she just puts her arms straight up and she just falls through your arms and it's hard".

One of the most interesting themes in response to this question was that three participants felt limited in their own abilities to interact with the CWDS and yet wanted to change themselves in positive ways. For example, one 16-year-old sibling of a CWDS who has a cardiac defect, as well as gastrointestinal and endocrine problems responded, "It wouldn't be anything with him; it would be something with me. I wish that I could be more patient... I've learned to be...really, patient more than most kids my age, but I do get frustrated with him". Another 15-year-old brother of a CWDS who had cardiac surgery and now has endocrine, gastrointestinal, and respiratory problems stated,

Well...I was...mean to him I guess. I just, I didn't want him to be around and so... when I was over with my friends or whatever and he'd come over I'd...be mean and try to get him to go away...I look back...I just shouldn't have been doing that.

Finally and surprisingly, the majority of respondents said they would not change anything at all about growing up with the CWDS. One 16-year-old sister of a CWDS who had a hemolytic disorder and cardiac surgery responded, “I don’t think I would change anything because I love him just as he is”. Another 19-year-old sibling of a CWDS who has neurologic developmental disorders responded, “You know, I don’t think I wouldn’t change anything. It’s certainly been rough and...we’ve had our share of troubles and what not, but she has taught me personally so much”. Another 16-year-old brother from the same family said, “She’s been a good influence, you know, changing. I think she’s changed me a lot for... the better and has just taught me... things that have just helped in my daily life. But I don’t think I’d change anything”.

Advice to Give Other Siblings

When asked, “If you had any advice to give to a sibling of a CWDS what would it be?”, most suggested patience. For example, one 17-year-old brother of a CWDS who has a cardiac defect, endocrine problems, and chronic ear infections said, “Be patient...It’s hard. Just keep your cool, they will eventually learn”. In addition, thirteen siblings said to deal with it, don’t worry what other people think, and go with the flow. Seven adolescents felt it important to love the CWDS. One 14-year-old sibling living with a CWDS who had cardiac surgery, respiratory, gastrointestinal, endocrine, and hearing problems said, “Just love them and try to understand a lot of the things that they’re dealing with”. Six adolescents said it will be hard but also good. Finally, five adolescents felt it important to work with the CWDS and spend time with the child.

Expectations for Adulthood

When asked, “Tell what you think will happen when the CWDS becomes an adult”, 19 participants felt the CWDS would live with their parents or a sibling. One 16-year-old brother of

a CWDS who has a repaired cardiac defect, respiratory, endocrine, gastrointestinal, and vision problems said, “I’m assuming he’s just going to live here until my parents die and then he’ll probably end up going around with me and my siblings”. In addition, 14 participants felt things would just stay the same (living at home), and three said the CWDS would not live as long as they would. One 18-year-old brother living with a CWDS who had cardiac surgery, and now has cardiac and gastrointestinal problems stated, “It’s my understanding that people with Down syndrome have this sort of life span...I guess that’s not good”. Interestingly, only one adolescent thought the CWDS would go to an assisted living center as an adult.

Discussion

The purpose of this research was to understand the perspective of adolescent siblings of CWDS who also have health problems so more appropriate nursing interventions can be offered for these siblings and their families. After analyzing the data, certain patterns and themes emerged about their experiences.

First, no specific theme arose regarding how the siblings learned the child had DS. Many were very young and said that they just grew up with the CWDS; they did not know anything different. Most learned about DS from their parents, doctors, and doing their own research. However, two siblings learned the most about DS through books and school rather than from their family. No research discussing how siblings learned about DS if they were living with a CWDS was found. However, Skotko and Levine (2006), discussed in their workshops how best to teach family members about disabilities, suggesting parents need to be open and honest in answering concerns brothers and sisters may have by using continuing dialogue that is structured around emerging questions.

Second, living with a CWDS affects all members of the family. The siblings noted they have added responsibilities and family priorities that may be very different compared to families raising typically developing children. Evidence shows families of CWDS do experience higher levels of stress than families with typically developing children and are subject to pileup demands (e.g., stresses, strains, transitions) along with unique challenges and increased responsibilities (Van Riper, 2000; 2007). Living with a CWDS may also require siblings to be a caretaker, teacher, or supervisor of the DS child (Mandleco et al., 2003). Other research also shows that both older and young siblings of children with disabilities assume expanded childcare roles compared to other children. For example, Cuskelly and Gunn (2003) found siblings of CWDS provided more care-giving, but also more care to younger children in the family regardless of disability. In one study, brothers and sisters of children with disabilities felt capable, helpful, responsible, and more mature than their peers who live with typically developing children (Skotko & Levine, 2006). The researchers considered these qualities very positive, but commonly acknowledged care-giving responsibilities should be limited because siblings may experience excessive pressure imposed upon them by themselves or their parents.

In addition, Dyke and colleagues (2008), found positive effects for siblings of CWDS were related to increased maturity, better tolerance and understanding of differences, added compassion and better appreciation of their own health and abilities compared to their peers who lived with typically developing children. Finally, Mandleco et al. (2003), believed siblings of children with disabilities had more self-control and cooperation/assertion compared to siblings living with children who do not have disabilities.

Third, participants felt ambivalent about living with a CWDS; there were both positive and negative aspects to the situation. These findings are similar to Cuskelly and Gunn (2003), who found a strong relationship between positive interactions with siblings and care-giving scores suggesting they regarded care in a positive light with more empathy and kindness, although there was also avoidance. These contradictory responses seem to be the best way to cope with a CWDS; the siblings realistically take the good with the bad, and learn from those situations. However, siblings in this study who saw both the positive and challenging aspects of living with a CWDS are those living with a child who has learning disabilities or behavioral problems including ADHD along with other serious health issues rather than just physiological health problems.

Fourth, since these CWDS had additional health problems, it was surprising most participants would not change anything in their lives, and believed they had learned much from the experience of living with a CWDS. This is true of other research as well; Cuskelly and Gunn (2003) found siblings of CWDS who took on more care-giving roles had high quality sibling relationships. Despite some evidence demonstrating when demands of childcare roles become excessive, there can be negative outcomes for siblings and the sibling relationship. Care-giving responsibilities were seen in a positive way by study participants. This was not expected. During adolescence, when teenagers are experiencing rapid growth and emotional changes, there often is more emotional distance and conflict between parents and adolescents as they interact more with peers than family, and are more 'self-centered' (Dunn & Fisher, 2009). In support of these current, yet surprising findings, Dyke and colleagues (2008) found adolescent siblings of CWDS were more mature compared to their peers, were more tolerant, more compassionate, and had a

better appreciation of differences of their own health, abilities, and understanding. In fact, Hodapp (2007) found families raising a CWDS compared to families raising children with other disabilities seem to cope better. The termed 'Down syndrome advantage' seems to have affected these participants.

Finally, these participants thought the CWDS would continue to live with their parents at home rather than living in a sheltered home environment with other CWDS after they reach adulthood. This is also surprising and may be related to the health problems these CWDS have because they may think that the CWDS will not live long. However, most CWDS today are able to live independently or in a sheltered situation away from the family. In addition, many CWDS are living much longer and more productive lives as they get older. Most public schools now integrate CWDS as they progress to adulthood (Hodapp, 2007; Rondal, Rasore-Quartino, & Soresi, 2004). In fact, Hanson (2003), found in a 25-year follow-up of 11 CWDS and their families, that six of these DS children were living in independent or semi-independent living situations and nine of them were able to work independently, be employed at least part-time, and perform many activities of adult living, including cooking, cleaning, and paying bills. However, if a CWDS has poor health, these activities and skills may be limited by struggling to stay alive. Dockerty and Reid (2009) also found mothers were concerned about their own aging and the implications it could have for their other children. All the mothers they interviewed expressed a desire for their young adult children with DS to become independent. They wanted to move their young adult children with DS to independent living, making sure all issues were taken care of before the parents died. Unfortunately, this may not be the case for some families raising CWDS in this study because of the health issues the children face and the added care needed.

Conclusion

When there is a child with a disability in the home, it affects the family globally. That is true for these families as well. After interviewing these siblings, the themes identified showed both positive and negative aspects of living with a CWDS who also had health problems and showed how resilient these adolescent brother/sisters are. Although there were difficulties, the adolescents still saw the CWDS as a very positive and rewarding experience in their lives.

Raising a child with a disability is hard on a family and influences every aspect of family life including sibling relationships, and it is important for nurses to be aware of these influences and aspects so more appropriate nursing interventions can be offered for these siblings and families. However, the majority of these adolescent participants would not change anything, and their additional responsibilities appear to influence them more positively than negatively. These adolescents also appear to be more aware of and socially accepting of others, even though adolescence is a time when one is more self-centered and peers seem more important than families. However, these adolescent participants have shown great maturity and seem to be aware that the needs of the CWDS may interfere with time they spend with peers.

Limitations and Future Directions

Consider these findings in the context of several limitations. Although 23 adolescents responded, they came from only 11 families. In addition, the participants were all Caucasian, from two parent middle-income families from the same geographic area, and with at least two other children in the family. The structure, size, and ethnicity of these families may be very different from other families in the United States raising CWDS. In addition, it is possible responses were influenced by social desirability because an adult conducted the interviews.

Despite these limitations, this research provides an important step in identifying areas of continued and needed interventions among healthcare providers, parents, and children. Future research should include additional families raising a CWDS from different socioeconomic backgrounds and geographic areas who have health problems and compare those with adolescents from families raising typically developing children to see if differences exist.

Nursing Implications

It is important for nurses to understand the perspective of brothers and sisters of CWDS so they can provide information about DS to these siblings early in their lives. Their experiences -- both positive and negative -- are an important part of family interventions. Therefore, knowledge gained from this study provides information for nurses and families to help better understand adolescent siblings' perceptions when living with a CWDS who also has serious health problems. Information gained can also assist nurses in supporting similar families by helping them gain better coping skills, learn more about the impact of DS on family, and provide information on stress management and nursing interventions that support family growth and development especially for adolescents who have the added responsibility of caring for and living with a CWDS. Nurses can also help families by providing them with resources for respite care, community services, and other services as needed to help CWDS reach as much independence as possible especially with their additional health problems. It is also important for nurses to educate parents about the perceptions their typically developing children have about their experiences living with a CWDS who also has serious health problems. Finally, it would be essential for nurses to educate siblings about options when their parents are no longer able to care for the CWDS who has additional health problems.

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Appendix A

1. Tell me how your family members learned about (the kind of disability the child has)
2. Tell me what it is like growing up with _____(name of child with DS).
3. Tell me about the health conditions your brother or sister with (add disability here) has.
4. Tell me how this health condition has affected you.
5. Tell me how this health condition has affected your parents.
6. Tell me how this health condition has affected your family.
7. What is easy about living with _____(name of child with DS)?
8. What is difficult about living with _____(name of child with DS)?
9. If you could change anything about growing up with _____(name of child with DS), what would it be?
10. If you had any advice to give to a sibling of a child with _____(the kind of disability the child has) what would it be?_____
11. Tell me what you think will happen when _____)name of child with disability) becomes an adult.

Appendix B

Family Information Questionnaire (One per family)

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 disability/chronic condition's birth date _____ Age _____ Gender _____
6. Name of sibling who is participating in the study _____
7. Sibling's birth date _____ Age _____ Gender _____

First names of all other children in your family (do not include sibling listed above or child with a disability/chronic condition).

<u>Name</u>	<u>Male/Female</u>	<u>Age</u>	<u>Birth date (Month/Day/Year)</u>
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

8. 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? Yes No
- f. If yes, who? _____

9. Age of parents: _____ Father _____ Mother

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

11. How many years of education has wife completed? _____ years

12. What is husband's current occupation? (job title) _____

Please briefly describe husband's duties

13. What is wife's current occupation? (job title) _____

Please briefly describe wife's duties

14. If husband has been employed outside of the home during this past year, has the employment generally been full time or part time? _____

15. _____ Number of hours husband works per week.

16. If wife has been employed outside of the home during this past year, has the employment generally been full time or part time? _____

17. _____ Number of hours wife works per week.

18. _____ Husband's religious preference.

19. _____ Wife's religious preference

20. 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

Please describe your child's disability

Appendix C

Date _____

ID # _____

Child with Special Needs Description**Adaptive Skills/Levels of Supports**

Please rate your child's need for support in the following areas, based upon the following criteria:

- 1 = Intermittent:** Supports are provided on an "as needed" basis, *temporary, infrequent* or *short-term*, in a few settings.
- 2 = Limited:** Supports are provided on a *regular basis* for a *short period* of time (not of an intermittent nature), in several settings.
- 3 = Extensive:** Supports are needed *regularly* (e.g., daily) in several settings and may extend over *long periods* of time.
- 4 = Pervasive:** Supports are *constant* and *intense* in all settings. They may be life-sustaining.

_____ 1. **Communication** (understand others and express self)

_____ 2. **Self-Care** (toileting, eating, dressing, hygiene, grooming)

_____ 3. **Home Living** (clothing care, housekeeping, cleaning, cooking, home safety)

- _____ 4. **Social Skills** (interact with others appropriately, cope with demands, obey rules, peer acceptance)
- _____ 5. **Community Living** (travel, shop, use public facilities, church, volunteer)
- _____ 6. **Self-Direction** (make choices, follow a schedule, seek assistance, resolve problems)
- _____ 7. **Health & Safety** (eating nutritiously, illness identification, basic first aid, physical fitness, taking medication, receiving home health care, follow rules and laws)
- _____ 8. **Academics** (writing, reading, math, science, health, geography, social studies)
- _____ 9. **Leisure** (play, recreational activities, personal choices)
- _____ 10. **Work** (part or full-time job, related work skills, money management, changing job assignments)
- _____ 11. **Mobility** (ability to get from one place to another, visit friends and family)

Classification & Intellectual Functioning

12. What is your child's *primary* diagnosis?

13. What *educational classification* is listed on his/her Individualized Educational Program (IEP)?

14. Please list *secondary* diagnoses.

15. What is your child's approximate IQ level?

Unknown Unable to determine

<25 <40 <55 <70 <85 <100 <115 < 130 <145 >145

(more questions on back)

Physical Health, Mental Health, Etiology Considerations

16. Please list any physical health related conditions your child has.

17. Please list any psychological or emotional difficulties (e.g., mental illness) your child experiences.

18. Please list the cause of your child's condition (if known) and your child's age when diagnosed.

Environmental and Cultural Contexts

Rate the extent to which your child’s living, leisure, and educational environments *facilitate* or *restrict* opportunities for community presence/participation, making choices, demonstrating competence, and gaining respect.

Environments	Facilitate				Restrict
Home	1	2	3	4	5
Neighborhood	1	2	3	4	5
School	1	2	3	4	5