



ABSTRACT

Introduction: Addison's disease is a rare chronic illness caused by adrenocortical insufficiency. Understanding the process of family adaptation to this chronic illness in a child will help practitioners enhance the ability of the child and family to cope with this stressful diagnosis.

Method: A qualitative descriptive case study methodology was used to explore the process of family adaptation to this chronic illness. Eight interviews were conducted with a newly diagnosed 11-year-old White girl with Addison's disease, along with her parents, grandparents, and siblings. Participant observations were made in the family's home. Drawings by the girl with Addison's Disease were included in the data analysis, along with an interview with the child.

Results: The overall theme of adaptation to this chronic illness is living a normal life. The family noted that after reaching some acceptance, they began learning how to manage the disease. This process was enhanced by seeking information about the disease and receiving the support of others; in addition, the child was affected by the acceptance of her peers.

Discussion: Recognizing factors that may influence the family's adjustment to the diagnosis of Addison's disease in a child will help to direct educational and support efforts by practitioners.

J Pediatr Health Care. (2003). 17, 301-310.

Adaptation to Addison's Disease in a Child: A Case Study



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The National Health Interview Survey on Child Health conducted by the National Center for Health Statistics estimates that 31% of children younger than 18 years of age, or almost 20 million children, have a chronic illness (Jackson, 2000). These chronic illnesses do not have a cure; therefore, "The goal of care is to minimize the manifestations of the disease and maximize the child's physical, cognitive, and psychosocial potential" (Vessey & Mebane, 2000, p. 27). Practitioners provide care to these children and their families to achieve this goal. Knowledge of the family's adaptation to the chronic illness can increase the practitioner's ability to intervene with the family as they learn how to cope with chronic illness.

One of the more rare chronic diseases affecting children is Addison's Disease. When a child is diagnosed with this disease, the child and family must learn to cope with a chronic disease. Because of the rarity of this condition, there is a paucity of information available to families and to the health care providers who care for them.

Addison's Disease, or primary adrenal insufficiency, is a rare disorder characterized by chronic adrenocortical insufficiency resulting in deficiency of glucocorticoids and mineralocorticoids (Sabol, 2001). Addison's Disease affects females two to three times more often than males, and onset most often occurs between the ages of 30 to 40 years, with 4 out of 100,000 people affected by the disease. Although the disease occurs rarely in children, it can occur at any age. Historically, the cause of Addison's disease was tuberculosis infection; however, since the introduction of antibiotics, the main cause of Addison's Disease has been autoimmune destruction of the adrenal gland (Sabol, 2001). Autoimmune adrenalitis is relatively more frequent in children than adrenal insufficiency as a result of infections,

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0891-5245/2003/\$30.00 + 0

doi:10.1016/0891-5245(2003)46

although occasionally the etiology may involve parasitic infections, cytomegalovirus, fungal infections, amyloidosis (deposits of waxy substance called amyloid in vital organs), and adrenoleukodystrophy (fat molecules collect in the adrenal glands) (Sabol, 2001).

The disease results in a lack of the glucocorticoids that aid the body's ability to handle stress (O'Donnell, 1997). Glucocorticoids are involved in carbohydrate, protein, and fat metabolism, carbohydrate and glucose storage, decreasing inflammation, and suppression of the immune response. Often a deficiency in mineralocorticoids also exists, which leads to increased renal sodium loss and potassium reabsorption, resulting in decreased intravascular volume, vascular tone, cardiac output, and renal perfusion. These symptoms in turn result in lower arterial pressure, postural hypotension, and compensatory tachycardia, which, if left untreated, leads to vascular collapse and coma (O'Donnell, 1997).

The adrenal glands are controlled by the pituitary gland, which increases the production of adrenocorticotrophic hormone (ACTH) to stimulate the adrenal glands. Diagnostic findings for patients with Addison's Disease include low plasma cortisol and high plasma ACTH levels (Gance-Cleveland, 1999; O'Donnell, 1997).

The increased ACTH stimulates pigment-producing cells in the skin, resulting in darkened scars, skinfolds, and mucous membranes of the lips, mouth, rectum, vagina, and nipples and black freckles appearing over the face, forehead, neck, and shoulders. In addition to changes in pigmentation, early symptoms of the disease may include fatigue, decreased appetite, weakness, and hypotension. Children may exhibit a decreased level of activity and a drop in weight and a corresponding shift on the growth charts. Undetected, the disease may lead to anorexia, nausea, vomiting, and diarrhea, which in turn can lead to dehydration, dizziness, syncopal episodes, small heart, decreased cold tolerance, fever, abdominal pain, hypoglycemia, apathy, and mental confusion. Prolonged delay in diagnosis and treatment may lead to developmental issues with an impact on school performance because of decreased attendance and lethargy when in attendance. Adrenal crisis or acute adrenal insufficiency can

occur if a child remains undiagnosed or the child is given inadequate amounts of cortisol to deal with stress such as infection, exposure to cold, burns, trauma, surgery, or sodium loss resulting from perspiration (O'Donnell, 1997). Symptoms of adrenal crisis include hypotension as a result of decreased intravascular volume, severe renal insufficiency, electrolyte disturbances, metabolic acidosis, and hypoglycemia (Lenzer, 1998).

Complications of Addison's Disease include acute adrenal crisis, psychotic reactions, hyperkalemic paralysis, and exacerbation of the disease with pregnancy. Other complications include thyroiditis, hypoparathyroidism, pernicious anemia, and ovarian failure, probably caused by autoimmune disorders.

Addisonian crisis can occur with any stress; therefore, the dose of hydrocortisone is increased with any illness, emotional stress, physical stress, trauma, or surgery.

Treatment of the disease involves replacement of the missing hormones, most often hydrocortisone (Cortisol) and fludrocortisone acetate (Florinef) with a daily maintenance rate. Children take hydrocortisone, 12 to 15 mg/kg/day in two doses with two-thirds of the dose in the morning and one-third of the dose in the evening to duplicate the normal circadian rhythm (Gance-Cleveland, 1999). Addisonian crisis can occur with any stress; therefore, the dose of hydrocortisone is increased with any illness, emotional stress, physical stress, trauma, or surgery. Parents are taught to double or triple medication in anticipation of a stressful event (eg, tests, travel, and field trips) and to increase medication in the event of any

illness (eg, fever, vomiting, and diarrhea). Families are told to repeat the dose if the child vomits within 1 hour of taking the medication. The dose of fludrocortisone is 0.05 to 0.2 mg per day, and parents are instructed to increase the dose with exposure to heat and increased sweating. In addition, families are given hydrocortisone sodium succinate (Solu-Cortef) injections to have on hand at home and school in an emergency. Injections are indicated in a child who is unable to take medications orally or has an injury resulting in loss of consciousness (Gance-Cleveland, 1999).

Knafl and Deatruck (2002) described a process undergone by families of children with a chronic illness that, over time, led family members to come to view both the child and their life as normal. This normalization was defined as acknowledging the condition and its potential to threaten lifestyle; adopting a normalcy lens for defining the child and family; engaging in parenting behaviors and family routines that are consistent with normalcy lens; and interacting with others based on a view of child and family as normal. As noted earlier, little information is available on families' adaptation to Addison's disease in a child. The purpose of this case study is to explore the process of adaptation to this childhood chronic illness and come to an understanding of the similarities and differences in normalization when a child has Addison's Disease. In this case study, a child with Addison's Disease and her family members were asked to provide information on their adaptation to this chronic illness. Drawings by the child with Addison's Disease provide additional insight into the experience.

Ryan-Wenger (1998) supports the use of children's drawings as a projective technique, based on the assumption that drawings reflect a child's self-concept, attitudes, and conflicts and represent emotions or thoughts that children are unable or unwilling to verbalize. Spontaneous drawings provide important insights into the child's world; drawings requested by the nurse are a form of communication. The inclusion of the child's drawings provided insights into her experience with the diagnosis of Addison's Disease that might not have been fully understood without the drawings.

METHOD

This qualitative descriptive case study was undertaken to explore the process of family adaptation to Addison's Disease. The research question addressed in this case study was, "What was the process of family adaptation to the diagnosis of Addison's Disease in a child?" Tape recorded, unstructured interviews lasting 15 to 75 minutes were conducted with members of a family with a newly diagnosed 11-year-old White female child with Addison's disease. See the [Box](#) for questions guiding the unstructured interviews with the child, parents/grandparents, and siblings. Eight interviews were conducted with an 11-year-old school-aged youth and her parents, grandparents, and 9- and 13-year-old siblings. Consent was obtained from parents and grandparents, and verbal assent was obtained from each child prior to the interview. Interviews were conducted in the home. As the interviewer was leaving the home at the conclusion of the interview, the child with Addison's disease offered to share several pictures and a poem about the disease. A second interview was scheduled with that child to obtain an explanation of each drawing and the poem. Participant observations were conducted to obtain information on family interactions and the interactions of siblings.

The data were transcribed verbatim and placed on the Ethnograph, a software data management program that facilitates sorting and analyzing the data (Seidel, Kjolseth, & Seymour, 1988) for managing and sorting the data. The data were analyzed by using the constant comparative method (Lincoln & Guba, 1985). The central theme that emerged was the family's ability to adapt to the child's illness and live a normal life. Factors that made this adaptation possible were identified. A review of the relevant literature on chronic illnesses in children was used to compare and contrast the emerging concepts from this study and their relationships. These emerging concepts were discussed with the families and further modified until the investigator, informants, and a colleague found them credible.

RESULTS

The overall theme in adapting to this chronic illness for this family was being able to live a normal life. The family de-

BOX Guidelines for unstructured interviews

Interview of Child with Addison's Disease

- If you met a child who just found out that he or she had Addison's Disease, what would you tell him or her that it is like to have this disease?
- What is the hardest thing about having Addison's Disease?
- How have you learned to take care of yourself with this disease?
- What have other people done that has been helpful to you since you found out that you had Addison's Disease?
- What is the biggest change that you have noticed since you got Addison's Disease?

Parent Interview

- What has it been like to have a child diagnosed with Addison's Disease?
- How did you and your family learn to cope with this disease in your child?
- What was the most helpful to you and your family?
- What was the hardest part of having a child with Addison's Disease?

Sibling Interview

- What is it like to have a sister with Addison's disease?
- What has been the hardest part of having your sister get Addison's Disease?
- If you had a friend who just found out that her sister had Addison's Disease, what would you tell her it is like?
- Is there anything that you would tell that friend that might help her?

scribed a process of adjusting to the diagnosis that was influenced by the severity of the child's condition and involved a grief process similar to that described by Kubler-Ross (1969). After reaching a level of acceptance, the family began a process of learning to manage the disease that was influenced by seeking information about the disease and receiving the support of others; the child was also influenced by the acceptance of peers (see [Figure 1](#)). A final theme that unfolded during interviews with siblings was the impact of the disease on them.

The central theme that emerged was the family's ability to adapt to the child's illness and live a normal life.

Adjusting to the Diagnosis

The process of adjusting to the diagnosis of Addison's disease in a child was described by family members using

concepts similar to those that Kubler-Ross (1969) described in her work with terminally ill patients. The child and her family described denial regarding the significance of the disease. One family member said, "The hardest thing for me is some of my family members don't seem to want to accept the fact that this is a lifelong thing...they say she might outgrow it."

A parent shared this story depicting the child's **denial**:

One day when they only had a half day of school and she was running late, I told her to go take her medicine. She said she didn't have time and that she only had a half day and she would take it when she got home...When she got home she had a headache, was crabby, and didn't feel very good. Then she knew she had to take (her medicine) in the morning when she gets up.

The family reported feelings of **anger** and **guilt** when they took the child to the emergency room for the third time prior to the diagnosis of Addison's Disease.

Sometimes some of the nurses made me feel like I did something wrong. They always used to ask me why I let her get so sick and how

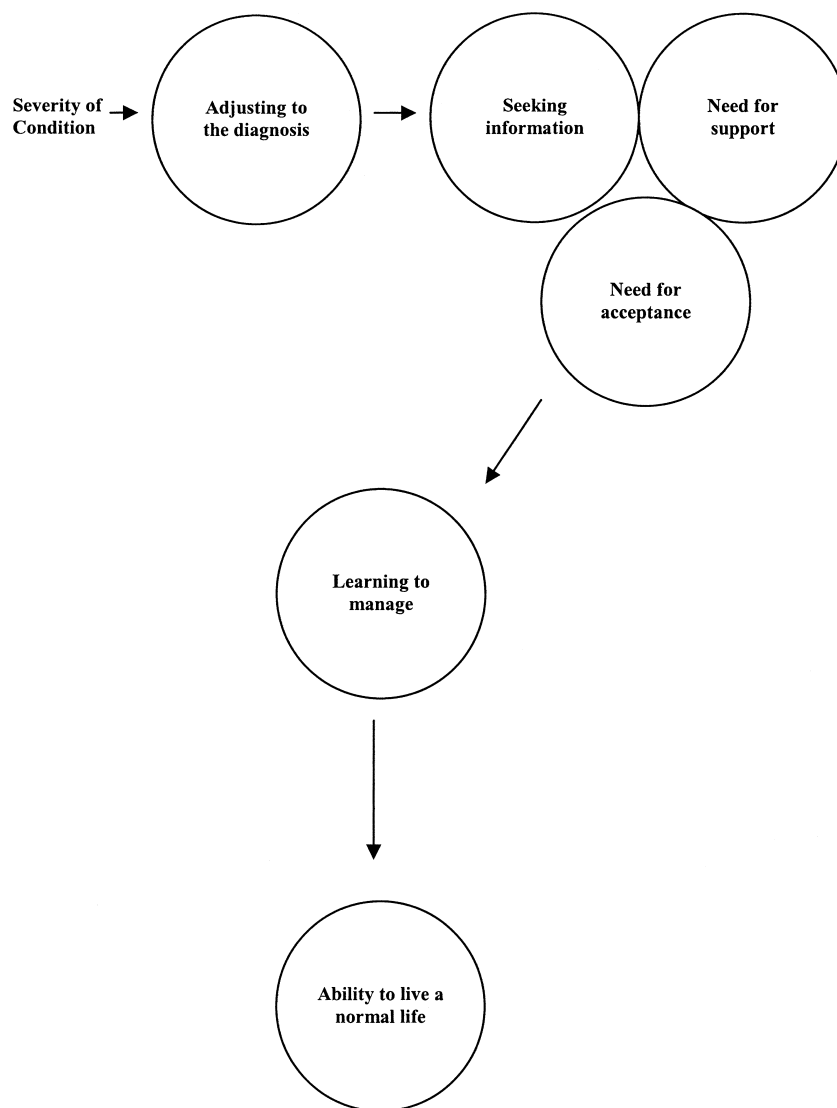


FIGURE 1 Process of adaptation to Addison's Disease.

come she was so skinny. They would want to know what she was eating, and when she had pneumonia they wanted to know why we waited until she was so sick until we brought her in.

The grandmother also reported feeling angry:

One time I was in the emergency room with her because her mother was unable to get there, and the nurses wanted her to stand on the scale to be weighed and she was too sick to stand up; she would get dizzy, and so I was holding on to her, and they said don't hold on to her. I was really mad they put her through that.

A parent also described **bargaining** when her child was very sick and they were not sure of a diagnosis: "I thought if they could just figure out what was wrong I could deal with it, but not knowing was driving me crazy."

The parents described their child's period of **depression** after the diagnosis: "The only time she has ever been really upset was the day that they told her (the diagnosis), and then she cried and told me that it wasn't fair and that she didn't want to have a disease."

Depression was also evident in the picture this child drew of herself in the hospital (Figure 2). She described the drawing: "This is the picture I drew when I got out of the hospital one time before they knew what was wrong with

me. I was sad because I didn't want to go there (the hospital). I was scared. I didn't know what they were going to do."

A factor influencing the family's ability to **accept the diagnosis** was the **severity of the child's condition**. The child was hospitalized in the intensive care unit in critical condition before the diagnosis of Addison's Disease was even considered, and they experienced multiple hospitalizations and many painful procedures (Figure 3). The family experienced the stress of the possible death of the child prior to the diagnosis and initiation of therapy. The diagnosis provided a sense of relief for this family. "She was in the hospital five different times before they diagnosed her (with Addison's Disease), and every time she was more seriously ill. She was in intensive care two different times with pneumonia and dehydration."

This family had been told there was a good chance the child had anorexia nervosa or a brain tumor, and many other serious diseases had been ruled out prior to the diagnosis. Therefore, Addison's Disease seemed less threatening after the family had worried about these other diseases and had struggled for months with the unknown etiology of the child's frequent, severe illnesses.

The child also was aware of the severity of her condition, as evidenced by the drawing in Figure 4, which the child explained as the following:

That is the picture of the ambulance that I rode to the hospital in because I was too sick for mom to take me in the car. I woke up one morning when I had just gotten out of the hospital and I didn't feel good at all. I told my mom take me to the doctor right now. I went and laid down in my mom's car and she carried me into the doctor's office. The nurse couldn't get my blood pressure and so she hurried out to get the doctor and she took one look at me and told my mom to come out into the hall. They came back in and the doctor said that I think you know that you have to go back to the hospital and I said, "Yes." But she said, "You have to go in an ambulance because I want you to get there fast," and I said, "Can you get me a helicopter, cuz I just wanted to get there fast."

Acceptance of the diagnosis is also reflected in this statement: "I felt much better (after being diagnosed with Addison's Disease) because I thought maybe they could help it and maybe I wouldn't have to come to the hospital so much." Acceptance was also reflected in the series of drawings done by this child. In the first drawing, done prior to diagnosis, the girl is crying and upset at being sick (see Figure 2). After diagnosis and stabilization, the pictures depict a girl in her hospital room watching television and visiting with clowns (see Figure 5).

Adjusting to the diagnosis of Addison's Disease appeared to be a complex process for this family. They explained that their ability to adapt was enhanced by the resources available to them (via online information and the National Organization of Rare Diseases) and the coping behaviors they were able to use, such as looking at the positive aspects of the situation.

Seeking information about the disease. Another step toward adapting to Addison's Disease was obtaining information about the disease and what it meant. The child relied on her parents for information or interpretation of the information that health care professionals provided:

When you first find out that you have Addison's Disease, it's hard to understand until someone explains it more, so you have your parents explain it a little more. They were using big medical terms for it and I didn't understand.... One time I had a CT scan and the man (a medical resident) goes, "Well it's just a simple procedure; it's just going to cut through your brain" (her eyes are like huge saucers as she is recalling the situation)...then I kinda got scared and my dad told me what he was talking about. That they're just going to take pictures of your brain.

The parents also expressed a need for information to increase their ability to cope with the diagnosis and care for a child with Addison's Disease. They described obtaining information from other parents, medical professionals, the public library, a hospital library, and the National Organization of Rare Diseases. The mother said, "It's probably

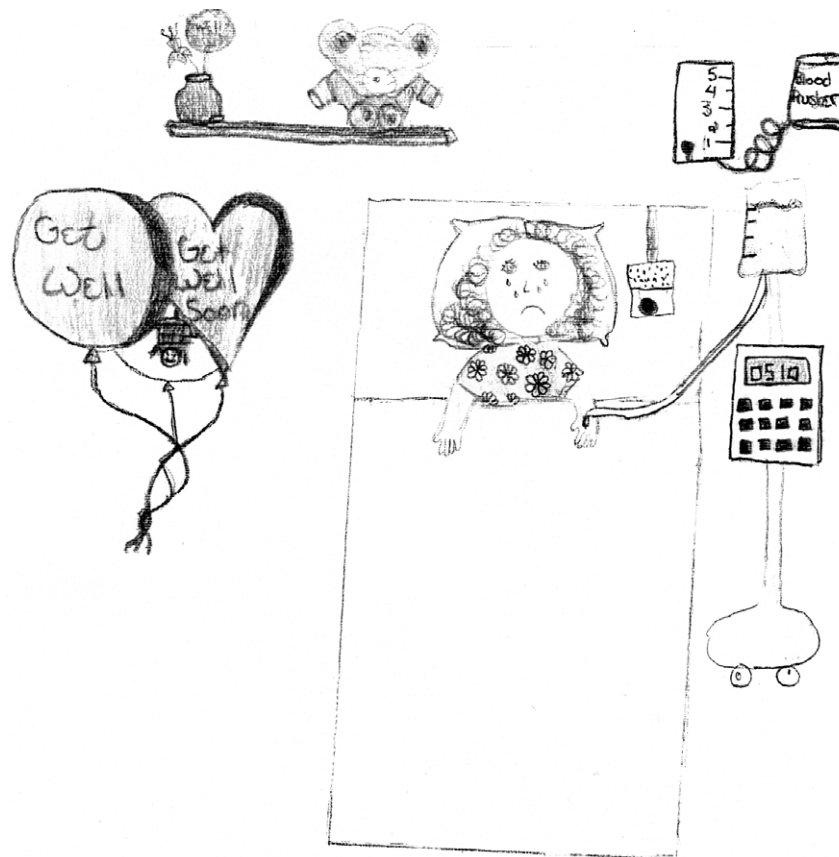


FIGURE 2 Adjusting to the diagnosis: Depression.



FIGURE 3 Accepting the diagnosis influenced by severity of illness.

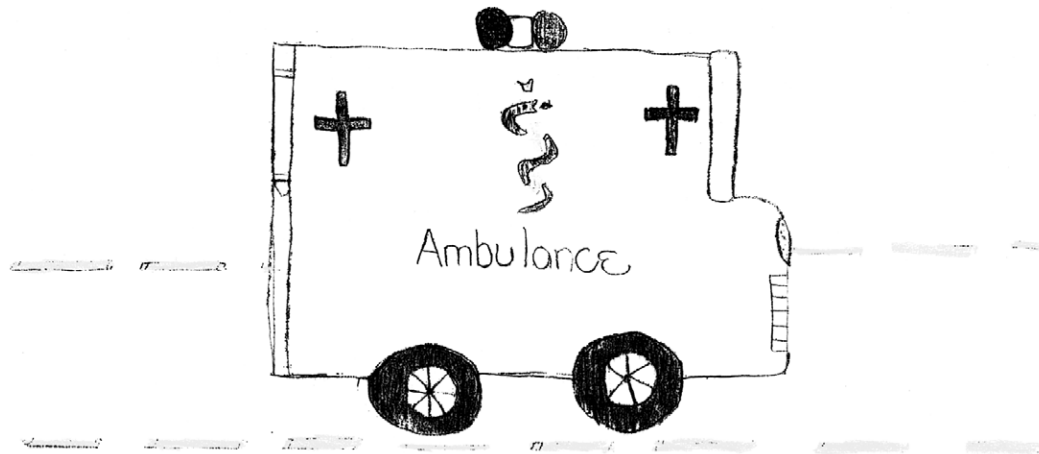


FIGURE 4 Severity of diagnosis: Emergency hospitalization.

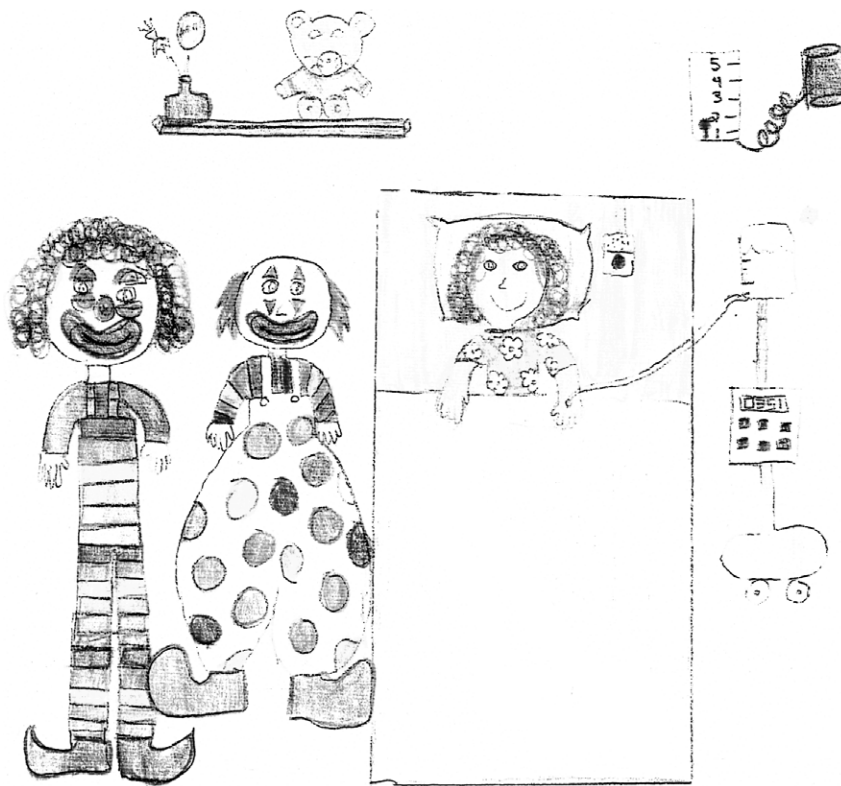


FIGURE 5 Acceptance of the diagnosis.

been easier for me to accept that she has it because I have a friend whose son has it. The sickest he's ever been was before he was diagnosed and he's had it for eight years." Much of the information families obtained did not come from health care professionals.

Learning to manage the disease. The mother described her fears when her

child was first ill, shortly after being diagnosed with Addison's Disease.

The first time she got sick she was running a fever of 101°...her energy level was wiped out and she curled up in a little ball and went to sleep and it scared me, and I tripled her cortisone and within 4 hours she was fine. And I guess since I saw the fast

turnaround with just tripling her medicine I realized that she was going to be okay.

The child also recognized her responsibility in managing her care. The girl explained learning to manage the disease in another one of the pictures (Figure 6):

That's me taking my medicine at home. That pill box is pretty big, but I wanted you to see it. The red thing is my pill crusher, the other thing is the pill box. The pills were hard to crush between two spoons, so my dad got me the pill crusher. I crush the pills and mix it with applesauce so I can take them because I can't swallow pills too good. My dad is buying me a pill crusher to keep at grandma's house. She has frozen applesauce and I mix it with that.

Need for Support

One facet of the coping process identified by this family was a need for support for the child with Addison's Disease and the family. The mother reported, "Just the moral support, I would have never made it without my sister being there all the time."

Her child reported, "Well, my mom had a best friend and her son has it and he kinda told me how to accept it, so it wasn't as hard. He helped me a lot."

Need for Acceptance by Peer Group

The child with Addison's Disease also described a need for acceptance by the peer group. She said:

One thing that bugs me is I wonder why kids would treat me different just because I have some disease. It kinda gets me upset...I don't think its right to do cuz I know if I had a friend (with a chronic illness) I wouldn't do that... some of the kids treat me different cuz they think it is contagious or something. Cuz I had a friend who was really close and then when I came back (from the hospital) and she found out (about the Addison's Disease) we're not that close. When I'd go up to her she'd just kinda say hi, and walk away with a different friend. That didn't make me feel too good.

Living a Normal Life

An additional factor that became apparent during the interviews was a commitment to do whatever was necessary to ensure that the child would live as healthy and normal a life as possible. The mother of this recently diagnosed child said she was able to accept the diagnosis when she understood that her child could live a normal life with good management.

And that's another thing that I read ...that really made me feel more comfortable about accepting it all, it said that if you have good doctor-patient relationship and you follow through on your therapy that she can live a perfectly normal, full life. That it's the people who don't do what the doctors tell them to do that have problems.

The child's parent describes the importance of living a normal life: "I really try to make her feel like she can do anything she did before." Adaptation to the disease was also influenced by the child's perception of their ability to live a normal life. The child explained the importance of living a normal life: "I would tell another kid...that you just act normal, it's nothing. All you have to do is take medicine. It's not like different diseases, and if they ever needed a friend to talk to they could talk to me."

The child with Addison's Disease adapted to this chronic illness when she discovered the ability to control her disease, which allowed her to live a normal life. The family's stories indicate dedication and commitment along with confidence in their ability to ensure their child would live a normal life.



FIGURE 6 Learning to manage the disease.

Impact of the Disease on Siblings

A final theme that emerged was the impact of the disease on siblings. Although the parents did not think the illness had an impact on the siblings, interviews and observations of the siblings revealed worry about the sibling with Addison's Disease, guilt when playing too rough, an increased level of responsibility, and jealousy over special treatment for the Addison's Disease patient.

The siblings said that they worried about their sister with Addison's Disease: "I was worried when she was in the hospital that she might die, because she looked so bad and stuff."

Increased responsibility was evident in this sibling's statement: "Now every night before bed I ask her, 'Did you take your cortisone?' Cuz she gets crabby

when she doesn't get her medicine, and I don't want her to get sick again."

Sibling rivalry or jealousy emerged in the family: "It ticked me off when dad bought her a new bike and he said he would buy her new softball stuff and not me."

FINDINGS COMPARED WITH EXISTING LITERATURE

Knafl, Breitmayer, Gallo, and Zoeller (1996) described five family management styles (FMS) in families with a school-aged child with a chronic illness. The five FMSs differed in the family's definition of the illness, management goals, and approach and illness consequences (see Table). The FMSs (thriving, accommodating, enduring, struggling, and floundering) represent a continuum of difficulty families experience

TABLE Relationship between adaptation to Addison’s Disease in a child and Knaf’s defining, managing, and consequences of childhood chronic illness

Themes*	Subthemes	Case study findings
Defining themes		
Parental views of child	Normal, problem, tragic	Living a normal life
Illness view	Life goes on, ominous, hateful, uninformed	Learning to manage
Child’s view of health	More healthy, equally healthy, less healthy	Living a normal life
Managing themes		
Parenting philosophy	Accommodative, sheltering, minimizing, inconsistent	Learning to manage
Management mindset	Confident, burdened, inadequate, observer	Accepting the diagnosis
Management approach	Proactive, reactive, compliant, uninvolved	Learning to manage
Self-care behavior	Competent, deficient, unconventional	Learning to manage
Consequence themes		
Parental mutuality	Present or absent	Adjusting to the diagnosis
Illness dominance	Yes or no	Need for acceptance by peers
Future dread	Present or absent	Not addressed in case study
Child consequences	No big deal, intrusive, worry	Living a normal life

*Themes and subthemes obtained from Knaf & Deatrick, 2002.

rience in managing a child’s chronic illness. Findings from this case study suggest that the support and education provided to the family in the adaptation process may influence the family’s ability to adopt a more favorable FMS. Learning to manage the disease was consistent with a proactive management approach versus the reactive, compliant, or uninvolved management. The child’s role in learning to manage the disease was consistent with competent self-care behaviors described by Knaf et al. The theme of living a normal life is consistent with parents viewing the child’s identity as normal and child’s perception of the consequences of the disease as no big deal (see Table).

The findings from the current study about the impact of the severity of the illness on adjusting to the disease are consistent with Horner’s (1997) description of overwhelming uncertainty while waiting for a diagnosis and relief when a diagnosis was made. The categories that emerged within the theme of adjusting to the diagnosis—denial, anger, bargaining, depression, and acceptance—are consistent with the stages of grief as described by Kubler-Ross (1969) in her work with terminally ill adults and also observed in families with severely ill children (Kubler-Ross, 1999). In contrast to the literature on adults with chronic illnesses who are frequently faced with isolation (Burkhardt, 1987), the child with Addison’s

Disease said that coping was influenced by her peer group’s acceptance.

Families in this study described seeking information as the next phase after accepting the diagnosis. Similarly, Shepard and Mahon (2000) suggest that having a diagnosis leads to a search for information about causes, treatments,

The role of the child in learning to manage this disease and the need for acceptance of his or her peer group are important aspects of care for children with Addison’s Disease.

and effects of the child’s condition. Also consistent with the findings of this study was Craig’s (1983) model of coping behavior in chronic illness, which includes the use of both personal and extrapersonal resources.

Gibson (1988) used Lazarus and Lauer’s theory on stress and coping as a

framework for understanding parental response to coping with a chronic illness such as cystic fibrosis. Although the parents experienced degrees of stress in meeting the illness-related demands, they coped with it through the help of available resources and action-oriented and intra-psychic behaviors. Findings from the current case study are consistent with Gibson’s theory of family coping with chronic illness in a child. Coping depended upon the resources the family had available and the behaviors they employed. In the current case study, resources that facilitated coping included information and support of friends and family. Also, focusing on the positive as a means of coping was evident in interviews with both the child and parents: the diagnosis was better than not knowing, it was better than some of the diseases that had been ruled out, the child was grateful the medication could be taken orally instead of by injection, and they were relieved the child could live a normal life. Learning to manage as described by these families is consistent with Gibson’s (1988) description of coping, which involved drawing on their own resources and feeling less overwhelmed. Another aspect of the study consistent with Gibson was the parent’s commitment to and love for the child as a strong motivating force to do one’s best to deal with the difficulties. Family members who believe they can do what is needed are less likely to be threatened

or to feel helpless or hopeless in stressful situations (Gibson, 1988).

In contrast to the findings in the present study, Shepard and Mahon (2000), in their discussion of chronic childhood illnesses, stated that coping patterns, concurrent stressors, and culturally determined values about health and illness affect the family's response to the diagnosis of a chronic illness. They suggest that visibility of the condition, potential for functional limitations, and presence of mental disability influence a family's ability to cope. In the present case study, the family with a child with Addison's Disease did not mention cultural influences, the visibility of the condition, or the presence of mental disability as influential factors. However, similar to living a normal life, Shepard and Mahon suggest that expectation of suffering for the child, uncertainty about prognosis, previous experience with chronic illness, and family perceptions about the condition influence coping in the family.

In addition, learning to manage the disease is consistent with the framework by Strauss et al. (1985) for understanding chronic illness, which delineates key problems in living with chronic illness, including prevention of medical crisis, management of crises if they occur, control of symptoms, and carrying out prescribed regimens.

Finally, consistent with the present study, Barbarian (1995) reports that siblings experience a variety of stressors and that parents have difficulty in accurately assessing the coping of siblings, and Morrison (1997) reports that most siblings are stressed during the chronically ill child's hospitalization.

DISCUSSION

Many consistencies were found between the findings of this case study and the literature on chronic childhood illnesses; however, because of the rare nature of Addison's Disease in a child, literature on the adaptation to Addison's Disease could not be found in the literature. This case study suggests that the family's experience with this rare chronic disease is similar to the experience of other families with other chronic conditions. This family received care from nurses who were not familiar with the disease and therefore provided very little information or guidance. Information from this case

study can be used to enhance the practitioners' information on this disease and the family's adaptation to the Addison's Disease.

Much of the information that the families in this study obtained did not come from health care professionals, in part because this rare disease had not been seen in a child before by many of these providers. Practitioners need to be aware of the sources of information that patients are using and the accuracy of that information, and they need to understand the process of adaptation to Addison's Disease for a family. This case study revealed the need for information so the family could adapt to the illness. Lack of familiarity with

Practitioners need to be aware of the sources of information that patients are using and the accuracy of that information, and they need to understand the process of adaptation to Addison's Disease for a family.

Addison's Disease may interfere with the practitioner's ability to provide information and support families at this difficult time. Thus, familiarity with sources of information and identifying factors that may influence the family's acceptance of the diagnosis and the process of adjusting to the diagnosis will direct education and support efforts. In addition, the role of the child in learning to manage this disease and the need for acceptance of his or her peer group are important aspects of care for children with Addison's Disease. The nurse practitioner may want to discuss with the child how he or she is managing the disease, as well as what friends

have been told about the disease and how supportive they have been. A practitioner who recognizes the family's need for support and the child's need for acceptance may provide the family with information on support groups or put them in contact with another family that has a child with Addison's Disease. Referring families to the National Organization for Rare Diseases (www.nord.org) is a good way to increase their knowledge about the disease. With information from families about the importance of the child's ability to live a normal life, the practitioner can reinforce the positive prognosis with good management.

Finally, the practitioner should be aware of the impact of the disease on siblings and the parents' probable lack of awareness of this impact. During well-child examinations, youth should be screened regarding chronic illness in their families and the impact of the disease on them. Visits with chronically ill patients should also include an assessment of the family's response to the child's chronic illness.

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