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Improving care for children with Down Syndrome: Nursing interventions

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Frederik Meijer Honors College Senior Project

Improving care for children with Down Syndrome and their families: Nursing interventions

Down Syndrome (DS) is a genetic disease that affects thousands of families. Children with DS often require more medical care since there are over 100 anomalies associated with DS (Phillips & Boyd, 2015). Without proper knowledge of DS, it is difficult for healthcare workers to provide effective and relevant care. This paper will focus on physical differences of people with DS, emotional coping in families of children with DS, along with interventions for physical and behavioral health that nurses can implement.

DS Background

Typically, everyone knows a person who has DS. However, simply knowing someone with DS does not mean that one holds enough knowledge of the disorder to provide optimal medical care. It is important for nurses and other healthcare providers to have a strong understanding of what DS encompasses and how it impacts the body. DS is the most common chromosomal disorder. Normally, it is not inherited, but occurs during cell multiplication and division. In order to have a diagnosis of DS, there must be extra genetic material on chromosome 21 (Phillips & Boyd, 2015). During pregnancy, there are many screening tests that are available. Some of these tests are invasive and pose a high risk to the fetus. Other screenings can lead to false positives (Phillips & Boyd, 2015). Ultimately, it is up to the parents and physician if screening tests for DS are performed. Once a positive diagnosis is determined, there are many ways for healthcare providers to support the child with DS and the family.

Without adequate support, the physical and mental health of the child with DS is at risk. Parents and families are also at risk of experiencing high stress levels and fatigue. Evidence shows that 55% of parents with a child with DS have to cut back on working hours or quit their

jobs compared to parents of a child with other special needs (Phelps, Pinter, Lollar, Medlen, & Bethell, 2012). Clearly, changes in the care of children with DS must be made for them to live their best lives. An intimate knowledge of physical differences children with DS have, as well as, common problems that occur in families is required to provide optimal care.

Physical Differences

There are many physical differences that are associated with a DS diagnosis. Being aware of these distinctions is critical for proper care. Without knowledge of differences, a child's needs may be neglected.

Hearing Loss

Hearing loss is highly prevalent in children with DS. It is estimated that between 38% and 78% of children with DS experience hearing loss. Park, Wilson, Stevens, Harward, and Hohler (2012) wanted to know if newborns who passed their hearing test developed hearing loss later on. They found that 101 infants who initially passed their test developed conductive hearing loss (Park et al., 2012). Knowing results of this study means that nurses can recommend to parents whose infant already passed their test to be re-tested in a few months. Unfortunately, researchers found that the length of time from initial screening to a confirmed diagnosis spanned between 485 to 601 days (Park et al., 2012). This length of time is unacceptable, and nurses must advocate that children with DS are given proper follow-up care. Of 33 children who were diagnosed with conductive hearing loss, 25 experienced normal hearing after insertion of ventilation ear tubes (Park et al., 2012). It is clear that quality of life can be improved for many kids given a proper diagnosis and timely intervention. Hearing loss is just one common complication that children with DS experience. The risk for impaired thyroid function increases during childhood and must also be routinely assessed

Thyroid Function

Proper thyroid function is important for many aspects of health. Thyroid hormones regulate neurodevelopment, growth and skeletal development, as well as metabolism (Iughetti et al., 2014). It is common for newborns with DS to experience a mild hypothyroid state from decreased thyroxine concentration. It is possible for this hypothyroid state to persist throughout childhood (Iughetti et al., 2014). Realizing that children with DS can have mild hypothyroidism is important information, however, it can also mean that some providers may dismiss lower levels of thyroid hormones. The probability that a child with DS will acquire thyroid dysfunction increases from 30% at birth to 49% at ten years old (Iughetti et al., 2014). Providers must stay vigilant to diagnose any thyroid dysfunction problems. Diagnosing thyroid dysfunction can be difficult because some symptoms mimic DS manifestations. Impaired intellectual development, decreased linear growth, dry skin and fine hair, and excess weight are common indications of both diseases (Iughetti et al., 2014). As a child ages, providers should routinely check thyroid function to ensure that they do not miss a thyroid dysfunction diagnosis. Nurses should advocate to providers to reassess any abnormal thyroid function tests. Nurses also must recognize that another unique susceptibility that children with DS have is to illness. Proper prevention and treatment of illness in DS patients is critical throughout their entire lives.

Infection Risk

Infections can be deadly, which is why it is important to prevent infection but also treat aggressively if needed. During the first year of life in a child with DS, naïve T helper cells, cytotoxic cells, and B-lymphocytes are lacking. It is possible that T cell levels will normalize with age (Bertrand, Doan, & Steele, 2013). All of these cells are necessary in fighting off illness. “Children with DS have more frequent infections and slower resolution of illness as compared to

other children” (Bertrand, Doan, & Steele, 2013, p. 1003). Other than having lower levels of immune cells, some possible reasons that children with DS are more susceptible to infection are from anatomical anomalies, gastroesophageal reflux, and neurological etiologies (Bertrand, Doan, & Steele, 2013). Assessing symptoms as they manifest is imperative to early treatment. Otitis media and respiratory tract infections are very common (Bertrand, Doan, & Steele, 2013). Recurrent otitis media infections affect up to two thirds of children with DS. Recurrent infections can lead to conductive hearing loss, so early aggressive treatment is crucial to preserve hearing (Bertrand, Doan, & Steele, 2013). Parents and caretakers are vital in identifying early symptoms of discomfort in their children. Nurses must educate parents about the importance of bringing their child to the provider for early treatment if they suspect an illness. Although nurses must be vigilant in the physical care of children with DS, they must also realize that the family unit will have unique emotional needs that need to be cared for as well. The way a family copes with a diagnosis of DS will impact that child’s entire life.

Emotional Coping

The way in which a positive diagnosis of DS is delivered will influence a family’s perception of the disease. In order for healthcare providers to have the best influence on a family, they should emphasize the positive characteristics of DS (Choi, Lee, & Yoo, 2010). Researchers found that mothers who heard positive features of DS when told of the diagnosis were more optimistic about raising their child. Unfortunately, many parents reported to researchers that providers put more emphasis on the negative aspects of DS rather than the positive (Choi, Lee, & Yoo, 2010). It is important that both caregivers are present at the time of diagnosis so they can hear the same information and are able to process it together. Parents will likely have feelings of guilt, shame, and social isolation after learning the diagnosis (Choi, Lee, & Yoo, 2010).

Providers should stress that it is not the parents' fault their child has DS and support them emotionally. It will likely take time for parents to overcome overwhelming feelings of having a child with DS and providers must be prepared to answer any questions the parents will have on how their lives may be impacted (Choi, Lee, & Yoo, 2010). There must be a balance of how much information is given to parents to not overwhelm them, but also meet their current needs. Nurses shall continually assess how parents are reacting and proceed accordingly.

Family Coping

After a child with DS is born, nurses can play a crucial role in helping the family unit adapt. Successful family adaptation occurs when the family is able to balance the needs of the family, the child, and other family members (Van Riper, 2007). Nurses can aid in this balance by providing a safe environment for parents and caregivers to verbalize their frustrations or conflicting emotions (Van Riper, 2007). Having a safe environment to do so means that parents will not be judged for their feelings. Nurses can help families identify stressors, community resources, coping strategies, and effective means of communication for the entire family. Nurses can also discuss ways to reduce the stress and demands on a family (Van Riper, 2007). During a typical visit to the provider's office, nurses can accomplish all of this in a short period of time. Nurses are able to provide the family with resources, like humor, flexibility, and support groups, based on their knowledge of what was beneficial for a different family (Van Riper, 2007). Many families reported that raising a child with DS resulted in positive experiences for all family members (Van Riper, 2007). If the family unit is struggling, the nurse can remind the family what unique, positive traits DS has brought into their home. Daily life is not always going to be stress free, so nurses must be able to provide parents resources to help aid in relieving stress.

Marital Quality

Raising a child with DS will likely be demanding, and it is not uncommon for stress to negatively impact a couple's marriage. In order to decrease stress, respite care should be utilized frequently. Social support outside of the family can increase the mental health of parents caring for a child with a disability (Norton, Dyches, Harper, Roper, & Caldarella, 2016). Research demonstrates that there are positive effects on the well-being of a child when respite care is utilized. Additionally, children with disabilities commonly have increased social skills from respite care (Norton et al., 2016). Respite care not only benefits the parents and child with DS but benefits the siblings as well. When using respite care, siblings are able to spend more time with their parents and do things that they may not typically be able to do (Norton et al., 2016). Norton et al. (2016) suggests that respite care helps lower stress and improve marital quality by allowing couples to spend time together. Parents that utilized respite care stated they experienced lower stress levels, increased relaxation and a state of renewal (Norton et al., 2016). In order to provide the best possible care for a child with DS, every caretaker needs breaks. Allowing caretakers time for themselves is important for maintaining a positive state of mental health. Due to respite care workers making minimum wage, a high turnover rate is common (Norton et al., 2016). Nurses can advocate for respite care workers to receive competitive wages for their work. It is also important that nurses inform families what respite care is. Without the knowledge of this service, families will not know to utilize it and may suffer from high levels of stress. Nurses can be huge advocates for patients and their families. There are many physical limitations that a child with DS has, and nurses must advocate to the health care team for their patients to keep them safe.

Physical Health Interventions

Nurses in the acute care setting must be prepared to care for children with all types of conditions. Proper knowledge of DS is necessary for nurses to provide safe, effective care for children with DS. Physical differences that children with DS have will greatly impact the care they should receive while in the hospital. Nurses can take specific steps to provide the best care while children with DS are in the hospital.

Acute Care Setting

The care a nurse provides during a hospitalization is very different from outpatient care. Nurses must adjust their practice appropriately to safely care for a child with DS. It is necessary that nurses carefully position children with DS since they have generalized laxity of joint ligaments (Kyle, 2012). Without careful positioning, damage can be done to the cervical spine. The head and neck are particularly susceptible to joint subluxation (Kyle, 2012). If a child is going in for surgery, the nurse must remind the surgical team to carefully position the child to prevent joint injury (Kyle, 2012). Some infants with DS may experience increased feeding difficulties due to low endurance and low arousal. Infants may have trouble sucking and swallowing and are at a particularly high risk for aspiration (Kyle, 2012). The nurse caring for the infant must closely monitor nutrition and feedings. If necessary, the nurse might suggest enteral feedings to ensure the infant is receiving proper nutrition (Kyle, 2012). Older children might also have difficulty with nutrition if they cannot adapt to new textures or cups. If a simple solution is not evident, nurses can consult with speech language pathologists and nutritionists to coordinate care (Kyle, 2012). These are only a few challenges that nurses can face while caring for a child with DS in the hospital. Injury prevention and proper nutrition are two services that

are expected during a hospital stay. Nurses must stay educated on both of these matters specific to children with DS, as well as other factors to improve care.

Preoperative Care

Surgery in children with DS has more complications than in children without DS. It is vital that the nurses preparing the child for surgery, as well as the nurse in the operating room, are aware of these extra risk factors. The surgical journey for a child with DS may be longer, so nurses shall reassure parents that a longer surgery does not mean the outcome of the surgery is jeopardized (Kyle, 2012). There are various factors that could cause a longer length of surgery. Breathing difficulties are not uncommon for children with DS and nurses must anticipate the need for an endotracheal tube, noting that the tube required may be smaller than expected (Tonge, 2011). Because of these structural differences causing breathing abnormalities, careful planning of anesthesia induction is crucial (Kyle, 2012). Before a child has the scheduled operation, there will be preoperative evaluations scheduled. Nurses must emphasize to caregivers that it is vital these evaluation appointments are kept (Tonge, 2011). During these preoperative evaluations, the anesthesiologist and surgeon will evaluate the patient to carefully plan. Without evaluations, providers are unable to set forth a detailed plan, and the child's care is compromised. If the child has diabetes, they should be scheduled for surgery early in the day to limit the hours fasting (Tonge, 2011). While the child is preparing for surgery, nurses should incorporate a child's routine into the plan of care to decrease anxiety and improve cooperation (Tonge, 2011). After surgery is complete, nurses must work with caregivers to identify pain in the child. Children with DS often have higher pain thresholds and difficulty discerning pain location (Tonge, 2011). Caregivers should be able to help nurses identify pain so that it can be treated properly. Surgery can be scary no matter what age a person is. Adapting a child's home

routine can help make surgery less scary and educating parents to expect a longer procedure can help ease their minds as well.

Improving Care

There are always ways that care can be improved. Harris, Abbott, and Jukes (2012) found that many health care workers view children with disabilities as “problems that need to be solved” (pg 27). Clearly, a lot can still be improved. In order for children with DS to receive the best care, staff must adopt a compassionate and non-judgmental approach to care (Harris, Abbott, & Jukes, 2012). The “Getting it Right Charter” was developed to improve care for children with disabilities. It states that family members and caregivers should have an active voice in the plan of care for their child, and that their wishes should be heard and respected. Additionally, a liaison nurse specializing in learning disabilities should be available at each hospital (Harris, Abbott, & Jukes, 2012). This liaison nurse can work with the healthcare team and help provide continuity of care. The charter also urges hospitals to educate all staff about learning disabilities (Harris, Abbott, & Jukes, 2012). One way to ensure continuity of care is create a passport of sorts for children with DS. This passport can contain information about how to communicate best, how to assess pain, and some likes or dislikes of the child (Harris, Abbott, & Jukes, 2012). After a few changes of shift, some of this information may be lost in report and negatively impact care. If a document contains all of this information and goes with the patient, then all providers will be aware of the information. For hospitalizations that are planned, a visit to the hospital is recommended beforehand. This allows the child to see the environment they will be in and possibly meet some of their providers, making the transition easier on the child (Harris, Abbott, & Jukes, 2012). Nurses and other staff must continually assess the care they provide and see if there are ways to improve. It can be challenging to care for a patient with DS

if someone has no previous experience doing so. Staff education is vital to improve patient care. Hospital staff must be aware of what they can do to improve care for children with DS, and parents must be aware of ways that their child's life could be improved.

Behavioral Health Interventions

Communication is key to any relationship. A child who cannot communicate cannot have their needs addressed in a timely manner. It is vital that parents establish strong communication skills in their children. Some children and young adults with DS may experience behavioral problems. Some of these problems could be the result of ineffective communication. Day occupations may help combat negative behaviors because positive behaviors are modeled from peers (Foley et al., 2014). Parents and caregivers are fundamental in establishing their child's communication skills and helping them obtain a day occupation.

Gesture Interpretation

Everyday people communicate with each other. Whether people are having an in-person conversation, utilizing sign language or electronics, messages are being sent and received in order to come to a mutual understanding. Without communication, it is impossible to know what someone wants or needs. Children with DS make unique gestures to identify objects (Dimitrova, Özçalışkan, & Adamson, 2015). If parents identify what that object is and give it a verbal label, then children with DS are just as likely to enter that word into their spoken vocabulary within the next year as a typically developing child (Dimitrova, Özçalışkan, & Adamson, 2015). Children with DS, do however, make unique gestures less often than typically developing children. This makes it even more crucial for parents to assign a word for that unique gesture. Since there are fewer chances that a child with DS will give unique gestures, there are fewer chances to translate those into words. If these opportunities are missed, the child's vocabulary development will be

delayed (Dimitrova, Özçalışkan, & Adamson, 2015). Nurses should emphasize that translating gestures immediately after they occur allows the child to more easily make the connection between the verbal label and the object of interest. Assigning verbal labels for unique gestures early in a child's development will allow that verbal label to be used each time the gesture reappears. As with typically developing children, repetition helps a child enter a word into their vocabulary (Dimitrova, Özçalışkan, & Adamson, 2015). Communication is a skill that a person will need throughout their entire life. The receiver may interpret gestures and other non-verbal signals correctly but being able to use verbal communication is the simplest. Nurses can teach parents that they can aid their children in developing their vocabulary as soon as they begin making unique gestures, like pointing to a specific object. Sometimes, not being able to communicate what one is thinking or feeling can lead to outbursts or other behavioral issues. Interaction and communication with peers who do not have DS or behavioral problems can provide a good model to individuals who may be struggling with their behavior.

Day recreation versus open employment

Managing negative behaviors is stressful on parents and caregivers. Some parents may try having their child attend a day recreation program to improve these behaviors. If they make this choice, these behaviors will likely get worse. Foley et al. (2014) found that adolescents and young adults who attended a day recreation program experienced increased problematic behaviors. They theorize that this is because of the lack of choice making opportunities, isolation and segregation from the community, and a lack of meaningful challenging activities (Foley et al., 2014). On the other hand, adolescents and young adults with DS and open employment experienced a decrease in problematic behaviors during the study. In their study, open

employment is employment in a setting with typically developing peers doing jobs that those peers could also perform.

Foley et al. (2014) believe that the open employment setting allows for modeling, observation, and imitation of typically developing peers that results in behavior improvement. Open employment has many benefits for adolescents and young adults with DS. Knowing that open employment can promote positive behaviors, it should be carefully considered when designing interventions for people with DS (Dimitrova, Özçalışkan, & Adamson, 2015). Nurses must educate parents on the benefits of open employment. Without doing so, parents may lack the awareness of how open employment can benefit their child with DS. Parents can aid their child in receiving an open employment position and advocate for them. Decreasing problematic behaviors can change the life of someone with DS. If problematic behaviors make it difficult for them to socialize with peers or groups of people, individuals may feel isolated. Open employment can give a young adult with DS purpose and feelings of inclusion.

Conclusion

Overall, taking care of a child or patient with DS will bring new challenges. If nurses are not aware of special care that children with DS require, then the child's needs may be neglected. Hospitals must work hard to improve the knowledge of nurses to ensure that they are properly prepared to care for a child with DS. Children with DS have unique physical features that put them at risk for injury that all nurses must be conscious of when providing care. Nurses in the acute care setting and primary care setting should be familiar with the types of resources available for families of children with DS. After an initial diagnosis of DS, families will need extra emotional support throughout their journey of learning how to care for their child. Taking care of a child with DS adds extra stress to the family unit, but respite care can help alleviate

some caregiver strain and improve the family's functioning. Any parent is anxious when their child is admitted to the hospital. When nurses have proper knowledge of DS, they can help calm some of parents' fears and worries. All patients deserve care that is specific to their situation. Education is the only way to ensure that nurses have the proper knowledge to provide patients with optimal care. Hospitals must first recognize that many nurses lack the necessary knowledge to care for children with DS and then need to implement teaching programs. There are many intricacies of DS and the information provided here is only a glimpse of what nurses need to know in order to intervene appropriately and optimally.

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