Case Study #1: Gabriella Sanchez

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NUR 4050 OL30 Family Centered End-of-Life Across the Life Continuum

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 End of life is a very stressful time in any individual’s life and death does not discriminate by race, sex, age or wealth. When an individual faces such circumstances it involves them and their surroundings such as friends and family. It is especially poignant if it’s your own child who still is a toddler taking his/her first steps in their journey through life and is stopped short by a devastating terminal condition they didn’t inflict on themselves. Being a nurse we are trained to empathize with others but in the case of Gabriella Sanchez and her family; it is very challenging. When facing such a stressful event in the family every individual goes through a set of emotional/ mental trials. Trials that we must try to understand to the best of our abilities as health care workers by treating not only the patient but the family as a whole.

 Gabriella Sanchez was introduced to this world with a neurological disorder which caused her to have a developmental delay. She is just breaching the initiative vs. guilt stage of development physically but in actuality she is still at the level of trust vs. mistrust. Her neurological delay has hindered her recognition of her surroundings and familiarizing herself to those surroundings might not be an option for her. The case study focuses on her ability to only familiarize herself with family members. Lack of trust is an expected outcome due to slowed development but two very important aspects needed to be addressed are comfort and quality of life improvement for Gabriella.

 Based of Maslow’s hierarchy of needs; physiological needs deserves priority especially now that she requires total care. To provide comfort she is to be fed, bathed, and clothed as well as given security, frequent positioning and comfort. Then we need to include psychosocial interventions in order to provide love, affection and a sense of belonging. She lacks the ability to verbalize her feeling therefore needs affection, a sense of belonging and an importance in the family.

 A mother can sacrifice a lot for her children it’s an innate nature of a mother and Maria is a good example of this. She sacrificed her professional life for the care of her ill daughter giving up a decent income to help provide her comfort. She needs to have a strong support system throughout this very challenging issue. Maria’s stress can be described as the oppressive or worrisome load borne by people providing direct care for the chronically ill (Hunt 2003. p.28). Maria needs to know that she is loved and valued as a family member, she needs attention and intimacy. Since she is a working mother she needs a stable environment so she can eventually continue on trying to get re-employed. Lacking any social interaction may have an effect on her, so she needs to be able to keep in contact with her friends and go out. She needs emotional support whether she receives it from family for professionally. The physical strain needs to be reduced with a home health aide. The mother displays memory loss which signifies she has caregiver’s stress and it needs to be addressed.

 Jose Sanchez is Gabriella’s father who is also experiencing care giver’s strain by providing the financial funds in order to keep up with expenses. His role as the father is to provide safety and security. The father is feeling a sense of failure due to his inability to keep her protected from such devastating conditions. The feeling of weakness, helplessness, depression, financial burden and fear are affecting Jose. He needs a stable home environment where he can fully function at work and at home. He also requires emotional support from family, friends and professionally. Since he has such a financial burden he needs his physiological needs met such as healthy foods, habits and adequate rest. He also requires his companion to provide intimacy and love. The marriage might be suffering and if so it’s best to attend marriage counseling in order to correct and stabilize their relationship. Jose is also forgetting he has other children he needs to re-focus on which can help him reduce the caregiver’s stress. These many points need to be addressed in order for Gabriella’s family to have a fighting chance to give her the comfort she needs without breaking apart the family.

 Gabriella’s siblings are also coping with this situation according to their developmental stage and age. According to Erikson’s developmental task, Miguel who is 11 years old is at the industry vs. inferiority (6-12 years old) stage. At this stage young adolescents want to partake in certain tasks giving them a sense of responsibility. They strive for accomplishment and are very competitive. This is an age where most pre-teens Miguel’s age develop interaction skills and situations such as his families can lead to inadequacy and inferiority due to increased expectations/demands of them which they cannot meet (Wong 2009). He needs to know and feel he can contribute to the family needs adequately. Accomplishment is very important for Miguel and his parents have to appreciate his efforts. He needs his family to be there to provide support, love and a sense of value to him. He also would require emotional support and counseling. Counseling is good for Miguel to vent out his feelings and in return the counselor can help him develop coping skills. Also being a pre-teen he should be introduced to sports and physical activity to socialize and also it’s a great way to cope with stressors such as his sister’s illness.

 Rosa, Gabriella’s sister is suffering from a similar problem accept she is in an older age bracket therefore a more advanced developmental stage. Erikson’s identity vs. role confusion (12-18 years); she is 14 years old. Adolescents go through a lot of physical changes and are preoccupied with how they look and how their friends look at them. In this part of their life they ponder about past, future and present roles. They want to incorporate their ideals, beliefs and values with those of society. If the adolescent isn’t able to identify their place in society, role confusion occurs. If successful in this stage of their life they develop a sense of devotion and fidelity in relationships and an individual with core values and ideologies that will contribute positively to society (Wong, 2009). Rosa needs emotional support from the family as well as love and a feeling of value. She needs time to spend with friends and have regular teen activities such as, shopping, movies, etc. She also needs counselor’s intervention in providing an ear for her to vent too and to identify stressors/coping factors.

 Maslow’s hierarchy of needs emphasizes the need to fulfill Gabriella’s physiological needs and as a nurse we should focus on these needs. Pain management, due to the PEG tube insertion, increased incidence of pressure ulcers and muscle spasms in legs/arms. There’s a need to total physical care due to increase skin care, hygiene, preventing excoriation of skin from incontinence, PEG tube and pressure ulcers. She needs her body to receive proper nutrition via PEG tube which very important also to make sure she receives proper amounts of fluid. Gabriella is also in danger of developing DVTs due to immobility and requires physical therapy as well. Advocating for an occupational therapist as well as a speech therapist is also very important. Most importantly since she has developed paralysis of the vocal chords that might lead to possible aspiration and as a precaution I would educate the family on suctioning the patient to keep airways patent as a safety precaution.

 Financially I would advocate for Gabriella to have any type of disability benefit that would help her healthcare costs. I would ensure she has the proper health insurance giving her and her family a reduction in financial burden. She needs to be given home schooling in order for her to learn at her own pace, speech therapy can help develop her vocals again. The main thing here is to give her a fighting chance regardless of her condition. “Healthcare providers should focus on the child’s abilities rather than disabilities. Doing so can help maximize their developmental level and outcome”. “To maintain optimal level well-being, children with disabilities have elevated and ongoing needs for therapy, and primary and specialty care (Perrin, 2002)”. Providing these needs will give Gabriella as sense of emotional/developmental stability and this will contribute to her comfort during her care.

 As healthcare providers we should focus on the strengths of the individual instead of weaknesses. Since she is in the stage of Trust vs. mistrust I would recommend gaining her trust by focusing on her preferences and what makes her comfortable. We need to manage pain and assess/ reassess pain because it is so important to gain her trust and provide comfort. This could be done by recognizing cues such as, facial grimacing or other alternatives. Pain management does not always involve medication intervention; there’s music therapy, art therapy, warm/cold compress and in her age bracket we can incorporate toys and favorite TV shows. We also need to take into consideration religious/ spiritual needs of her and her family. In order to maintain comfort family education is very important of equipment that might be used such as suction catheters.

 There are resources that are available for Gabriella and her family and palliative care is one of many healthcare options that can provide comfort. World Health Organization states, “palliative care for children as the active total care of the child’s body, mind and spirit and involves giving support to the family”. The Palliative care nurse would start by doing an initial assessment of not only Gabriella but her family’s as well. this assessment would include being culture competent, psychosocial, socioeconomically, physical and spiritual aspects of her life. First step is to decide who will be part of the team who will provide Gabriella with the right physician, PT, chapel, social worker, HHA and nutritionist. The social workers are very important part of the process; including financial stability especially since there will be a need for special equipment and staffing. The right social worker will make sure spiritual needs are also meet through counseling. This counseling can provide the whole family with some stability by helping the ventilation of their feelings.

 The physician and nutritionist are going to provide management of pain and nutrition. Pain caused by the arm and leg spasms could completely disrupt the comfort levels of the child and PEG tube insertion mean special attentions to nutrition and hydration. There are other parts of the team such as volunteers and bereavement counselor. Volunteers give the rest of the family the chance to spend quality time together and bereavement counselor the opportunity to provide coping mechanisms for anticipated grief. Keeping these team members unchanged throughout her care would help with her developmental level of Trust vs. Mistrust.

 Gabriella’s healthcare would significantly change if she was older and we have to take into consideration the developmental delays. At the age of 21 it would be very difficult to care for an adult with developmental delays causing her to be an adult child. Someone with the same issues at that age would definitely be abusive physically and it would make it difficult to work with her. It would cost more because there would be a need for extra equipment such as a hoyer lifts, wheelchairs, and assistive devices. Straining due to weight during turning/ positioning would make it difficult to prevent pressure ulcers. She would require more staffing and because of her PEG tube insertion, kicking/ hitting when touched and need for more staffing she would be better suited for a long term care facility. If put in a nursing home she will be surrounded by more staff, more management equipment and the proper protocols needed to provide comfort not only to her but the whole family as a unit. Management equipment involves medical beds, assistive devices, hoyer lifts, physicians, medication management and pain management.

 Eric Erikson’s developmental stage would define her to be in identity vs. role confusion stage due to the delay in cognitive function. In this stage Gabriella needs social support since she will be developing a sense of self. Usually adolescents go through this stage and have the support of their peers and friends. Since she has lived a certain age it’s easier for her to invite friends she has made over the years to come see her. “With regard to bladder and bowel care, clean intermittent catheterization and timed bowel programs are the most frequent solutions with varying degrees of successful day-to-day management” (Johnson, et al.). This practice can increase the sense of self-worth and confidence. There are leg braces and physical activities that include sports with those with disabilities hindering their ability to ambulate on their own.

 Gabriella and her family have obstacles and these hurdles are a challenge that they should not have to face alone. I feel privileged to be part of a healthcare system that is able to provide the resources required to give them all a comfortable ride. As a RN it is my job to advocate for families in similar situations. I hope we can use her unique case as an example of how lucky we are to have health. The illness of one in a family will affect all those that love and cherish that individual but we need to keep in mind they are people with needs as well.

Bibliography

-Johnson, K., Dudgeon, B., & Walker, W. (2007, February 1). Assistive Technology Use among Adolescents and Young Adults With Spina Bifida. Retrieved November 5, 2014, from http://www.ncbi.nlm.nih.gov/pubmed/17194874.

-Wilson, D., & Hockenberry, M. (2009). *Virtual clinical excursions--pediatrics: For Wong's essentials of pediatric nursing, 8th edition*. St. Louis, Mo.: Mosby/Elsevier.

- Zerwekh, J. (2006). Nursing Care at the End of Life: Palliative Care for Patients and Families. Philadelphia, F.A Davis Company.

- Perrin, J.M. (2002). Health Services Research for Children with Disabilities. Milibank, Quarterly, 80, 303-324.

- World Health Organization. (2010). WHO definition of palliative care. Retrieved from http://www.int/cancer/palliative/definition/en.