Question 1

Introduction

This question discusses the barriers to identifying health needs of a child named Jenny, who is a 9-year-old female patient with Trisomy 21 and has a learning disability. Jenny has been admitted to the ward for dental extractions and has been accompanied by her mum who is a single parent. The main purpose of this essay is to identify the barriers faced by child and how these barriers can be overcome and to determine the role of the nurse during the hospital stay and preparation for discharge. It also discusses how a child's nurse can support Jenny's mother as she is a single parent.

Down syndrome is an inherited disorder, also known as trisomy 21 that is caused by abnormal cell divisions resulting in an extra full or partial copy of chromosome 21. This extra genetic material can cause changes in the development and physical characteristics of Trisomy 21 (Perelmutter et al., 2017, p.139). The severity of Trisomy 21 varies from person to person, resulting in lifelong mental retardation and developmental delays. It is the most common genetic chromosomal disorder and the cause of learning disabilities in children. It also frequently causes other medical problems, including heart and gastrointestinal disorders (Doran et al., 2017, p.459).

A better understanding of Down syndrome and early intervention can significantly improve the quality of life of children and adults with Down syndrome and help them live fulfilling lives. As women get older, the risk of having children with Down syndrome increases - women over 35 are usually advised to have prenatal genetic testing for their unborn children - but since young women have more children, 80 percent of babies born will have Down syndrome (Mkabile and Swartz, 2020,p.8504). In about 95 percent of cases, Down syndrome is caused by trisomy 21 - all human cells have three copies of chromosome 21 instead of the usual two. It is caused by abnormal cell division during development of egg or sperm (Mkabile and Swartz, 2020,p.8504).

Main Body

Barriers to identifying health needs of Jenny with a learning disability includedfacing issues in communication, social skills lacking, and rigid procedures or inadequate facilities amongst normal health care professionals in caring for the patients (Whittle et al., 2018, p.69). They have

emphasised barriers to identify healthcare needs of Jenny is communication difficulties, that is a result of trisomy. Staff are barred from counseling, inability of primary care physicians to conduct medical examinations, assess medications, and conduct blood tests and examinations, lack of health promotion and screening measures, and doctors' lack of understanding of the health needs of people with intellectual disabilities , it helps to mask the diagnosis (Campbell et l., 2021).

Staff have failed to adapt communication methods to the needs of patients, such as asking too many questions, speaking too quickly, providing too much information, and not giving patients enough time to respond. It is reported that communication difficulties or lack of confidence in patients affected their ability to express their concerns. Most patients find it helpful to have their guardian or advocate present during the consultation in order to facilitate understanding and communication (Oulton et al., 2018, p.1). Nursing staff's knowledge of how to deal with patient health problems is often overlooked. Caregivers actively manage patient care and are considered overly protective or “aggressive”. Five people with intellectual disabilities and nine nurses recalled cases when medical staff were unfriendly and treated them rudely. Accounts include sudden or condescending speech, unwanted employee appearance, swearing or disinterestedness. The lack of paid nurses or the behavioral problems of people with intellectual disabilities should also be strong inhibitors that prevent them from receiving “unnecessary” health advice. In addition, organisational barriers are manifested in the lack of supplies, as recommended in the mental health sector, which can lead to a decrease in the priority of those referred through screening (Truesdale and Brown, 2017).

Nursing staff complained that it was difficult to obtain information about the services available and that there was no clarity about referral channels and service structures (Campbell et l., 2021). Disputes between services about suitability and who should be responsible for the patient make it difficult to get care. In the UK, Public Services for People with Intellectual Disabilities is a multi-disciplinary service providing expertise in health and social care issues affecting people with intellectual disabilities (Truesdale and Brown, 2017).

The above mentioned barriers can be overcome by adopting following strategies.Communication barrier can be overcome if information is easy to read and accessible, or if communication book and health passport are given to Jenny that enabled carers and clinicians to communicate

alterations in the plan for Jenny' treatment. Many carers observed that services required to make rational adjustments to lodge theJenny's needs as she is at high risk for instability in cervical spine (McGarty and Melville, 2018, p.40). Dental surgeon ought to be aware of cervical spine instability in Jenny, particularly when taking into account protective or restraint stabilisation for potentially uncooperative and young children. The dental care staff should prioritise Jenny's treatmentto avoid having to wait so long before taking appointments. To make staff high alert computer records ought to highlight that Jenny has Trisomy 21 syndrome so that dental surgeon aware of risk of leukemia (Huot et al., 2019, p.1571385).

The oral care staff needto have effective training and sufficient knowledge about communication skills and circumstances, which are pertinent for Jenny with learningdisability. It is important that staff have better awareness of individual needs, including more person centred care. It is best to involve patients or caregivers in education. It is also recommended to contact hospital staff or mentally disabled nurses. They can advise clinicians or advocate for people with mental disabilities (Huot et al., 2019, p.1571385).

Another strategy that can overcome barriers is to support general practitioners with "reminder cards" with patient records. The map provides an overview of the support services available and evidence-based health problems that are important for the care of people with intellectual disabilities. However, after the trial period, there was no difference in prevention or referral between treatment and control groups (Wright et al., 2019, p.1499). There is some evidence that a "check-up plan" has successfully identified Jenny's health problems associated with trisomy 21, but there is no evidence that, and under what conditions, health screening can be effective as part of routine health care. It is important to note that success in identifying needs complements the evidence that Jenny subsequently obtains and uses for appropriate health care services (Alwhaibi and Aldugahishem, 2019, p.1524).

Nurses in oral care of Jenny with Trisomy 21 are recommended that they should use positive reinforcement and tell-show-do approach that may improve Jenny's behavioral outcomes and encourage her to practice oral hygiene methods at home (Nirmala et al., 2017, p.00248). The nurses also recommended that she should involving mother of Jenny so that she may help Jennyin maintaining healthy dentition, along with positive viewpoint on dental care. The nurse

should develop long-lasting relationships with Jenny children and provide her a “dental home” for her specific needs of health care (Wright et al., 2019, p.1499).

Conclusion

After exploring the scenario that was given above, it was found that Jenny with learning disability may create problems when giving routine oral care. The comprehensive appreciation of unique orofacial and medical considerations of Jenny may help dental surgeon give optimised care for other children with learning disability. Some children might require protective stabilisation to carry out an examination in a safe manner, or patients might have extensive oral care needs need detail care in the healthcare setting. The barriers to determine health needs of Jenny that were faced by oral health carers were issues in communication, social skills lacking, and rigid procedures or inadequate facilities amongst normal health care professionals in caring for the patients. As part of the ongoing process of effective and proper development of services, it is important to establish evidence of access to health care for people with learning disabilities. Despite the evidence gaps mentioned above, the review identified a major obstacle to an initiative to improve access to health care for people with learning disabilities. The focus is on identifying and implementing innovations that effectively overcome these barriers, which is critical.

The consultations also emphasised the role of oral care professionals in facilitating access to health services. In particular, it is reported that the usual way of providing medical care for children with severe learning disabilities is through the assistance of school nurses in their special schools. Often overlooked is how nurses deal with health problems. Nurses are active in caring for patients and are considered overly protective or “aggressive”. 5 people with intellectual disabilities and 9 nurses recall cases of unfriendly and rude treatment by the medical staff.Dental surgeon ought to be aware of cervical spine instability in Jenny, particularly when taking into account protective or restraint stabilisation for potentially uncooperative and young children. Oral care teams ought to confirm if cervical spine of child has been assessed. For children with instability of cervical spine and learning disability, caregivers and parents might offer valuable insight into good practices to safeguard the spine of child in such situations, which includes body positioning’s management during dental treatment and utilisation of pillows. The

oral care staff need to have effective training and sufficient knowledge about communication skills and circumstances, which are pertinent for Jenny with learning disability.

Question 2

Introduction

The purpose of this question is to provide Family and Child-Centered Care in the context of children with complex needs. This type of care includes medical equipment; for instance, special beds, hoists, aids, and bed equipment to assist with incontinence, hearing, or mobility. This is normally provided free. If a child needs healthcare treatment on regular basis, community nurses may support children's family. They may likewise assist with different treatment a child may need to perform for a child; for instance, giving injections or oxygen.Family-centered care consists of a set of attitudes, values and ways of delivering services to children with special needs and their families (Harrison, 2010, p.335). Family-centered care recognises that each family is unique; family is a constant in a child's life; they are experts in the abilities and needs of children. Families work with service providers to make informed decisions about services and support family and child adoption. Family-centered care takes into account the needs and benefits of all family members. While family-centered care is intuitive for many people, people in the service delivery system (including "service providers, parents, policy-makers, and managers") (Harrison, 2010, p.335). People may need evidence to support its effectiveness. Extensive research has been done on the effectiveness of family care for parents, children, and service systems. Future research ought to emphasised on aspects of "family-centered care" that have received relatively little attention; for instance, cultural diversity, and ought to examine this topic from different viewpoints and with broader results (Kuhlthau et al., 2011, p.136).

Main Body

"Family-Centered Healthcare" is the collaboration of patients, families, and caregivers in planning, providing, and assessing health care on the basis of four principles of the "Family-Centered Health Institute in Bethesda, Maryland", including:Health care providers must remember that patients are at a disadvantage and make every effort to ensure that patients maintain their dignity in the medical environment. For example, healthcare providers should remember to knock on the door before entering a room during an operation.In addition, after discussing options with the patient, members of the healthcare team should respect the patient's final decision. Patients, relatives and caregivers must provide all information. One way is to give patients access to their medical records. It was said that while it is not as widespread, some

family practices also allow patients to write on cards. “Health professionals can share information, but truly open communication also means accepting information (Shields et al., 2012, p.2559).

When information is provided to family members and patients, they will share resources and respect their choices, and it will be much easier for them to participate in their own care. When family members are admitted to the hospital, this principle is best shown in the ICU, which allows them to come and go as they please (Shields, 2017, p.14). It is important to involve consumers (people who use care services) when formulating policies, evaluating the quality of care or plans, and evaluating care practices. To realise family care, consumers must become committee members as full members. "They are not there as token members, but come in with personal experiences and ideas” (Segers et al., 2019, p.63).

The “biological ecosystem theory” is a theory that helps explain the impact on people and their families. This is “Bronfenbrenner's biological ecosystem theory”. The main tenet of this theory is that many different “backgrounds”, “environments” or “ecologies” (e.g. “schools, families, communities, peers, political systems, and social and cultural belief systems”) influence the development of children and adolescents (Segers et al., 2019, p.63). The model can explain multiple face-to-face environments or settings in a person's microsystem (e.g., family, school, peers); how relationships between environments (intermediate systems) affect what is in them. (For example, school-family interaction); and how the environment in which people do not exist directly (“macro- and external systems”) affects the environment of their microsystems (for example, how parental experience at work affects their family relationships). Thus, the model allows nurses to analyse human life, “the biological psychological characteristics of organisms, as a species or as individuals, are associated with their development, as well as the environment in which they live.” (Shields, 2017, p.14).

Another theory is "family systems theory." When it comes to understanding the family, family systems theory has proven to be very powerful. This theory belongs to the field of functional theory and shares functional methods that take into account the functions and dysfunctions of organisations and complex groups (Smith et al., 2017). The theory is that the family is best understood by thinking of the family as an ever-changing, dynamic and complex collection of subsystems, members, and parts of the family.Similar to how a mechanic connects to the

computer system of a faulty car to diagnose which systems are damaged (electricity, transmission, fuel, etc.), in order to repair it, the therapist or examiner will communicate with family members to diagnose how and where the problem occurred. Home systems are working and need repair or intervention.The theory also solves the boundary value problem. Boundary is the apparent emotional, mental, or physical separation between roles, subsystems, and people in a family. Boundaries are essential for the healthy functioning of the home (Shields, 2017, p.14).

A multidisciplinary team of practitioners and professionals from related departments, disciplines and healthcare work together to provide people-centered, coordinated support and holistic care. MDT composition varies by delivery model and environment, but may include: “professionals, general practitioners, physiotherapists, nurses, occupational therapists, social workers and pharmacists, an increasing number of volunteers and housing units. Navigators who provide social support rules by connecting people with local groups and community support services. An integrated and holistic approach to support and care requires the coordination of multiple services and interventions based on complex current needs, desired outcomes, and personal strengths (Smith et al., 2017). MDT plays an important role in overcoming professional boundaries and breaking down barriers to culture of competition and organisational difference. If successful, they can provide comprehensive, uninterrupted and continuous care services. Multi-institutional and interdisciplinary work involves the appropriate use of knowledge, skills and best practices from across disciplines and beyond service provider boundaries to redefine, reframe, and rescope the issues of social and health care delivery, and to conclude on the basis of an enhanced collective understanding (Phiri et al., 2020, p.10).

Conclusion

It is concluded that “family-centered care” takes into account the needs and benefits of all family members. While family-centered care is intuitive for many people, people in the service delivery system. Nurses also have an additional responsibility for building relationships with their families. Children are special patients and need special care, including treatment for the whole family. The concept of family-centered nursing care can increase patient and family satisfaction, increase their benefits, outcomes for patients and their families, increase the satisfaction of nurses and medical staff, and reduce medical costs. Most studies have shown that treatment

outcomes for patients and their families have improved. As nurses, we must remember to thank our families and their children and accept their differences.

Family oriented nurses have many benefits. Nurses need to build a harmonious relationship not only with the patient, but also with his relatives. This ensures optimal cooperation and interaction with the family, maximising the growth and well-being of each child. Parents and healthcare providers can work together to make more personal and informed decisions about the best treatment options for their children. The parents also received support and encouragement that were ignored by the old philosophy of caring. By helping parents cope with their children's illness, they can better care for their children and increase the stability of the parent-child relationship. Nurses have a better understanding of the family's capabilities and benefits, which allows nurses to strengthen and improve these skills so that patients receive the best possible care, even after they leave the hospital. When information is provided to family members and patients, they will share resources and respect their choices, and it will be much easier for them to participate in their own care. The “biological ecosystem theory” is a theory that helps explain the impact on people and their families. This is “Bronfenbrenner's biological ecosystem theory”. The main tenet of this theory is that many different “backgrounds”, “environments” or “ecologies” (e.g.“schools, families, communities, peers, political systems, and social and cultural belief systems”) influence the development of adolescents and children. Another theory was “family systems theory”, when it comes to understanding the family, family systems theory has proven to be very powerful. This theory belongs to the field of functional theory and shares functional methods that take into account the functions and dysfunctions of organisations and complex groups.

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