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Supporting children's development during extended hospitalisation for bladder exstrophy

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The extended hospitalisation and immobilisation of bladder exstrophy patients following primary bladder closure is largely known and accepted as the gold standard of care. Children who undergo this procedure spend an average of four to six weeks immobilised in the hospital, recovering. During this period, it is important to support the child in meeting age-appropriate cognitive, emotional, and developmental milestones. These developmental milestones for social and emotional development were first defined by psychologists Sigmund Freud, Erik Erikson and Jean Piaget, who all had slightly different theories of development and beliefs about when and how a child develops. Especially in the past few decades, these theories of development have been combined and utilised to measure the developmental growth of children, emotionally and cognitively, from infancy through adolescence.

Keywords: bladder exstrophy, development, developmental milestones, developmental tasks, theory

Definitions

Bladder exstrophy: A midline closure defect that occurs during the tenth week of pregnancy. As a result, at birth, the bladder lies exposed on the anterior abdominal wall.[1]

Development: Development refers to the progression toward maturity in mental, physical, and social markers.[1] Development indicates an increase in skill or ability to function (a qualitative change). A child's development is assessed by observing the child's ability to perform specific tasks, by recording the parents' description of a child's progress, or by using standardised tests.[1]

Developmental milestones: Major markers of normal development.[1]

Developmental tasks: Skills or growth responsibilities arising at a particular time in an individual's life, the achievement of which will provide a foundation for the accomplishment of future tasks.[1]

Theory: A systematic statement of principles that provide a framework for explaining a phenomenon. Developmental theories are theories that provide road maps for explaining human development.[1]

Introduction

This article aims to further educate healthcare clinicians and parents of children experiencing an extended hospitalisation following primary bladder exstrophy closure, regarding how to best support the child's continued development during hospitalisation, especially in the challenging state of immobilisation. The recommendations of care made in this article are based on Sigmund Freud's Psychoanalytic Theory, Erik Erikson's Theory of Psychosocial Development, and Jean Piaget's Theory of Cognitive Development.

Discussion

Children born with bladder exstrophy require multiple surgeries and many years of care to optimise their health due to this rare congenital anomaly of the urinary tract. Many such surgeries, including the closure of a primary bladder exstrophy, require an extended hospitalisation with immobilisation, which can feel especially restrictive and frustrating to a developing child. It is important to include support for the child's development in the medical plan of care, as children are constantly developing and are rapidly growing and changing. "Children with long-term illnesses often do not meet developmental milestones on schedule because achieving developmental tasks takes practice."[1] The additional risk factor of the child falling behind developmentally, in this case, their diagnosis of bladder exstrophy, makes it even more critical that these children receive additional support to continue appropriately and timely with development while undergoing necessary treatment.

Children who undergo treatment may also fall behind developmentally because of the health disparities they may experience. "Health disparities are the differences that exist when health is linked with social, economic, and/or environmental disadvantage. It adversely affects groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group, religion, socioeconomic status, gender, age, mental health, cognitive, sensory or physical disability, sexual orientation or gender identity, geographic location, or other characteristics historically tied to discrimination or exclusion."[2] In the case of paediatric bladder exstrophy patients, the primary health disparity patients face is a physical disability, their urologic congenital anomaly.

The recommendations to support the development of paediatric patients recovering from the primary closure of bladder exstrophy are based on the theories of development psychologists Sigmund Freud, Jean Piaget, and Erik Erikson. "Sigmund Freud (1856–1939), an Austrian neurologist and the founder of psychoanalysis, offered the first real theory of personality development."[3] Freud theorised that at each stage in a child's development, they are focused on a different body part, and failure to overcome their developmental task will harm the child's future development and can lead to problems related to that task in their adult life. Freud's stages begin with infancy and progress through adolescence. His

psychoanalytic stages are oral, anal, phallic, latent, and genital as children grow from infant, toddler, preschool, school-aged child, and adolescent, respectively.

"Jean Piaget (1896–1980), a Swiss psychologist, introduced concepts of cognitive development, or the way children learn and think."[4] Piaget theorised four stages, sensorimotor from zero to two years, preoperational thought from two to seven years, concrete operational thought from seven to 12 years, and finally formal operational thought beginning at 12 years. These stages focused on how the developing child thinks and learns, rather than Freud's focus on individual body parts and physical stimuli.

In addition to Freud and Piaget, psychologist Erik Erikson (1902–1994) developed another theory of development that has shaped current care recommendations for children. "Erikson is a psychoanalyst who discussed positive aspects necessary for healthy growth and development for a child to become a mentally healthy and productive adult."[5] Erikson believed that at each stage of childhood (infant, toddler, preschooler, school-aged child, and adolescent) the child must overcome a developmental task. The developmental task of infants is trust versus mistrust, for toddlers it is autonomy versus shame and doubt, for preschoolers it is initiative versus guilt, for school-aged children it is industry versus inferiority, and for adolescents, their developmental task is identity versus role confusion.

These developmental theories together help shape the medical community's understanding of how children develop and how to best support children while they develop. All three psychologists agreed that development occurs in a series of stages determined by age ranges. Children experiencing different stages will require different support, and children experiencing extended hospitalisations will require modified support to help continue their development while in the hospital.

Infants

Children aged one month to one year are considered infants, from the basic divisions of childhood.[1] Children in this age category are tasked with overcoming Freud's oral fixation, Erikson's trust versus mistrust, and Piaget's sensorimotor stages. According to Freud, infants must overcome an oral fixation, during which "the child explores the world by using the mouth."[1] Supporting infants at this stage includes providing oral stimulation, such as giving them pacifiers, allowing them to participate in thumb sucking, and breastfeeding from their mother. Hospitalised children may need temporarily modified support, such as pacifiers or bottle feeding, until breastfeeding can be more easily accomplished in the child's state of limited mobility with external immobilisation devices, such as casts or an external fixator. Moreover, there is a finite period in which oral feeding will be limited postoperatively. During this time, some form of oral stimulation, such as a pacifier, can be considered. While caring for a two-month-old infant in Uganda (Figure 1), medical professionals taught the mother of the patient to bottle feed to meet the needs of the immobilised child.

Infants must also overcome the developmental task of trust versus mistrust theorised by Erikson. During this stage of development, the child's "developmental task is to form a sense of trust versus mistrust…the child learns to love and be loved."[1] This task is overcome when the child has their needs met and is not ignored by their caregivers. The child should have a primary caregiver that they rely on, this person or a few people are typically the mother and father of the child. "When an infant is hungry, a parent feeds and makes the infant comfortable again. When an infant is wet, a parent changes their diaper and the infant is dry again. When an infant is cold, a parent holds the baby closely. By these simple processes, infants learn to trust that when they have a need or are in distress, a parent will come and meet that need."[1] For an infant that is experiencing an extended hospitalisation, this caregiver might also be a nurse that the child becomes familiar with and recognises. To help the child overcome this task, caregivers should spend quality time with the child. This may be modified for hospitalised children by having their primary caregiver with them when experiencing painful procedures and being comforted by their caregiver. By having their needs met, the child learns to trust and this will allow them to make connections with others as they get older and have successful relationships later in life.

According to Piaget, infants are in their sensorimotor stage of development. "Sensorimotor intelligence is practical intelligence because an infant is not yet able to use words and symbols for thinking and problem-solving at this early age."[1] Infants in the sensorimotor stage experience three stages within sensorimotor learning, called primary circular reaction, secondary circular reaction, and coordination of secondary reactions. During the primary circular reaction, when the infant is one to four months old, "hand-mouth and ear-eye coordination develop."[1] Supporting a child during this period can include providing toys, such as a rattle or a parent speaking to the infant, or playing a recording of a parent's voice for the child. These supports are appropriate for a hospitalised infant and can help them stay on track developmentally. Infants four to eight months old experience the secondary circular reaction stage of the sensorimotor stage, during which the "infant learns to initiate, recognise, and repeat pleasurable experiences from the environment."[1] To support the baby developmentally, the use of toys, such as mirrors and peek-a-boo, is recommended during this stage. The use of mobiles is another way hospitalised children can be supported during this stage, and using mobiles to play music provides an added source of entertainment for the baby. The final stage infants experience during the sensorimotor stage is the coordination of secondary reactions from eight to 12 months old. During this stage, "infant(s) can plan activities to attain specific goals." Toys to support the child during this developmental stage include toys such as nesting toys and blocks. Smaller nesting toys, such as cups, can be used to support a child after surgery, so they may play and continue to develop while conforming to a limited range of motion post-operation. The infant stage requires support to overcome each of these developmental tasks theorised by Freud, Erikson and Piaget.

Toddlers

After the infant stage, children progress to the toddler stage from age one to three years, from the basic divisions of childhood.[1] During this stage, toddlers are tasked with overcoming Freud's anal fixation stage, while progressing from Piaget's sensorimotor stage into the preoperational stage and working on overcoming Erikson's autonomy versus shame and doubt stage. Freud's theory of development theories that toddlers must overcome the anal fixation stage, which is when a "child learns to control urination and defecation."[1] To support toddlers so they can overcome Freud's anal stage, it is important to help children achieve control of their bladder and bowel, without emphasising its importance.[1] Children hospitalised due to bladder exstrophy will require different supports. A child born with bladder exstrophy will not gain control of their bladder like a child without the condition would. To support hospitalised toddlers, especially for an extended stay, it is important for parents and caregivers not to place importance or focus on the child's difference, but rather to love and support the child so they don't develop a fixation at this stage.

Toddlers are also working to overcome Erikson's autonomy versus shame and doubt stage. During this stage, a "child learns to be independent and make decisions for self."[1] This developmental task, for toddlers to gain a sense of independence, is overcome when the child is given the freedom to make decisions appropriate for a toddler. These choices could include allowing the toddler to pick out their own outfit. At the toddler stage, children begin to understand themselves as separate individuals, "...toddlers also realise they do not always have to do what others want them to do," which leads to them exploring their independence by pushing boundaries.[1] Hospitalised children can be supported during this stage by caregivers by being allowed to make decisions, such as picking an activity that they want to do, like colouring or playing with blocks. It is important to allow toddlers to have control and make their own choices, to help them develop confidence in their decisions with a sense of autonomy over their life. Overcoming this stage helps toddlers become confident in their decisions, which translates to the ability to be confident and successful throughout their lives.

In addition, toddlers are entering Piaget's preoperational stage. "The toddler period is one of transition as children complete the fifth and sixth stages of the sensorimotor period and begin to develop some skills of the *preoperative* period, such as symbolic thought and egocentric thinking."[1] To support toddlers during this stage, caregivers should help the child discover and experiment with new objects and events. At this stage, toddlers start to discover object permanence, so playing games like hide-and-seek, or hiding toys in spots the toddler can easily find, can help the toddler develop. Toddlers are egocentric, meaning they cannot understand that their point of view is not the only point of view, so being patient and understanding with the toddler is important. Hospitalised toddlers can be supported by caregivers playing games with them that demonstrate object permanence, such as placing a toy inside or behind something and then revealing to the toddler that the object is still there even when they cannot see that object. Toddlers experiencing extended hospitalisations need a lot of empathy and care from parents and other caregivers, due to their egocentrism. To support them, caregivers should encourage the toddler to talk about their feelings and display empathy and understanding to the child. This can be especially important for a toddler who is intentionally immobilised in the hospital and likely cannot understand the need for this restriction, often feeling frustrated by this constraint. Children aged one to three years must overcome the three stages (anal stage, autonomy versus shame and doubt, and preoperational stage) to continue to reach their age-appropriate developmental milestones.

Preschoolers

Children aged three to five years are classified as preschoolers from the basic divisions of childhood and are tasked with overcoming Freud's phallic stage, Erikson's initiative versus guilt stage, and continue to progress through Piaget's preoperational thought stage.[1] Freud's theory states that in the phallic stage, the "child learns sexual identity through awareness of the genital area."[1] To support preschoolers' development, caregivers should "accept the child's sexual interest, such as fondling own genitals, as a normal area of exploration."[1] Caregivers should accept that the child will become curious about and begin to explore their bodies and they should continue to support the child. While the specific implications of the effect of abnormal male genitalia at this stage of Freuidian development are unknown, it is important to support the child by providing love and understanding, especially when the child is displaying normal curiosity about and beginning to explore their body.

Preschoolers are also working to overcome Erikson's stage of initiative versus guilt. At this stage, the "child learns how to do things (basic problem-solving) and that doing things is desirable."[1] Children at this stage are learning how to accomplish tasks such as drawing, building things from blocks, playing dress-up, and doing other activities involving gross and fine motor skills. Parents and caregivers should support preschoolers by providing them with age-appropriate toys that allow the preschooler to explore, learn, and develop their new skills. The same supports can be put in place to support hospitalised preschoolers. Figure two shows the author with a five-year-old female patient recovering from her initial primary bladder closure (Figure 2). The child enjoyed colouring books and drawing, using stickers, playing with play dough, and having her nails painted. We worked on her breathing by doing modified incentive spirometry exercises, like blowing into a large syringe with a glove attached, using a brightly coloured paper party blower, and having her blow on her fingers to dry her nail polish (Figure 3). These activities supported the patient's development by providing her with activities that encouraged creativity and discovery through play.

Preschoolers continue to progress through Piaget's preoperational thought stage of development, and enter into a substage of preoperational thinking called intuitive thinking. Intuitive thinking contributes to many of the thinking processes that preschoolers use, including centring, a lack of conservation, and thought influenced by

role fantasy, assimilation, and magical thinking. Caregivers need to be aware that preschoolers are using these forms of cognition when responding to them in an empathetic manner. Children who are hospitalised may use magical thinking (the perception that animals and inanimate objects have thoughts and feelings) to describe where they are in pain, what they want to play with, or how they are feeling. Caregivers should be aware of this form of communication and respond to the preschooler with empathy and understanding. Preschoolers who overcome Freud's phallic stage, Erikson's initiative versus guilt, and Piaget's preoperational stage will continue to be on track developmentally.

School-aged children

Once children reach ages six to 12 years, they are considered school-aged.[1] School-aged children must overcome Freud's latent stage, Erikson's stage of industry versus inferiority, and Piaget's concrete operational thought stage. Freud theorised that in children in the latent stage of development, the "child's personality development appears to be inactive or dormant."[1] To help school-aged children continue to develop, caregivers should help them have positive experiences with learning, to help their self-esteem continue to grow. Children who are hospitalised should also be supported in this way, and learning should be encouraged and supported. Positive activities to support a hospitalised school-aged child's development are reading to the child, doing age-appropriate learning activities like math problems, allowing the child to explore their academic interests, and providing learning activities related to their interests.

In addition, school-aged children are working on overcoming Erikson's stage of industry versus inferiority during which the goal is for children to develop "self-confidence rather than inferiority."[1] To support children during this stage, caregivers need to encourage and instil confidence within the child by praising them for good work and making them feel like their work is important. "When they are encouraged in their efforts to do practical tasks or make practical things and are praised and rewarded for the finished results, their sense of industry grows."[1] Hospitalised children during this stage may be supported by receiving the same praise and encouragement when completing projects and tasks. One way to do this is to have the child complete art projects, like making a painting on a canvas, and then reinforcing to the child that they did a great job. While in Uganda, we supported the children by providing activities that included making paintings, creating drums out of art materials, and doing other crafts such as god's eyes. Children who are supported and successfully gain a sense of industry at this stage will have the skills to be successful and confident as they continue to learn and grow.

Children aged six to 12 years are also experiencing Piaget's stage of concrete operational thought. During this stage of development, children gain the ability to use systematic reasoning, use memory to learn broad concepts and subgroups of concepts, understand reversibility, recognise cause-and-effect relationships, and understand conservation. "A good activity for this period: collecting and classifying natural objects such as native plants or sea shells."[1] Caregivers should also help expose the child to other viewpoints by asking questions that require the child to consider how someone might feel in a situation from another perspective. Caregivers of hospitalised children should support the child in similar ways. Talking with the child about emotions, encouraging their interest in trying and learning new activities, and talking to the child about their personal interests are all ways in which school-aged children's development can be supported. Finding activities that an immobilised child can take part in while immobilised requires creativity and thoughtful modification, but is absolutely possible. These activities could include learning and playing card games and giving the child books to read about topics the child is interested in. School-aged children need to overcome Freud's phallic stage, Erikson's industry versus inferiority stage, and Piaget's concrete operational thought stage for their continued social and cognitive development.

Adolescents

Children aged 13–17 years are considered to be in the period commonly known as adolescence from the basic divisions of childhood and are tasked with overcoming Freud's genital stage, Erikson's identity versus role confusion stage, and Piaget's formal operational thought stage.[1] According to Freud's theory of development, adolescents must overcome the genital stage, during which the "adolescent develops sexual maturity and learns to establish satisfactory relationships with others."[1] To support an adolescent during this stage, they should be provided with the appropriate opportunities to form relationships. For hospitalised adolescents, caregivers should help the adolescent stay in touch with peers and friends and can include meeting new friends in the hospital environment.

Erikson theorised that the adolescent's developmental task in this stage of development is to form a sense of identity or face role confusion. During this stage "adolescents learn who they are and what kind of person they will be."[1] To support adolescents, caregivers should provide opportunities where the adolescent can discuss their feelings about events that are important to them and caregivers should offer support and praise for decision-making. When supporting hospitalised adolescents, caregivers should provide the same support. Caregivers should encourage adolescents to develop their sense of self through activities that they enjoy and are interested in. Caregivers should provide opportunities for the adolescent to become involved in activities they enjoy, for example, if the adolescent loves music the caregiver could help the adolescent learn to sing or play an instrument or help them get involved with peers who also enjoy music. With limited mobility, this may include something as simple as listening to different music and exploring their preferences. An adolescent needs to develop a sense of self through self-exploration and participation in activities they love, because "if adolescents cannot do so, they are left with role confusion or are left unsure of what kind of person they are or what kind of person they want to become."[1] It is incredibly important for caregivers to support the adolescent by allowing them to express themselves and pursue their interests.

Figure 1: Picture of a Ugandan two-month-old recovering from his primary bladder exstrophy closure being supported with the use of a mobile to aid the development of ear-eye coordination, which is developed during the primary circular reaction stage of sensorimotor development

Figure 2: Picture of a five-year-old Ugandan girl colouring and using stickers while she recovers from her primary bladder exstrophy closure; these activities support her by helping her to overcome Erikson's stage of autonomy versus shame and doubt by increasing her sense of independence and self-confidence through choosing which activities she wants to engage in

In addition, adolescents enter Piaget's formal operational thought stage, during which "...cognition achieves its final form."[1] Adolescents can use hypothetical and abstract thinking as well as scientific reasoning and deductive thought. A good activity to support adolescents is having "talk time" during which adolescents can sort through attitudes and opinions. Caregivers should engage in stimulating and interesting conversations with adolescents as they can use abstract thinking and deductive reasoning. Caregivers supporting hospitalised adolescents should provide the same support. It is important to discuss issues the adolescent is interested in, as well as validate their feelings and opinions. Providing support for adolescents to overcome Freud's genital stage, Erikson's identity versus role confusion stage, and Piaget's formal operational stage helps to ensure the adolescent finishes progression through the last stage of childhood development and can become a successful, functioning, and happy member of society.

Figure 3: Picture of a five-year-old Ugandan girl engaging in incentive spirometry and chest physical therapy with a nurse; these activities help the child to recover from her primary bladder exstrophy closure by encouraging her to practice breathing with fun tools like the noise maker toy in the picture

Conclusion

This article has outlined the social, emotional, and cognitive development of children based on the developmental theories of Sigmund Freud, Erik Erikson, and Jean Piaget. Children with bladder exstrophy who are required to undergo extended hospitalisation following the primary closure of an exstrophed bladder require modified support to continue to reach developmental milestones at a normal rate. It is incredibly important to provide the necessary support to these children and to help them continue to reach normal developmental milestones, as achieving these milestones helps to ensure the child will develop into a successful, happy, and healthy adult. Modifying support for hospitalised children will help them to achieve normal social, emotional, and cognitive development. These modifications for hospitalised children aged 0–18 years can be used by caregivers to support children and ensure their continued development while undergoing treatment.

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