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CE OSTOMY CARE

Growth and Development Issues in Adolescents With Ostomies

A Primer for the WOC Nurses

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Caring for the adolescent (13-18 years of age) with an ostomy presents multiple challenges. The purpose of this article is to provide strategies to assist the WOC nurse in minimizing the potential impact on growth and development for this age group with an ostomy. This is relevant to the WOC nurse since it is estimated that between 6% and 14% of all adolescents have symptoms of irritable bowel disease, and many will require an ostomy. Thus the WOC nurse will be called upon to provide care to this age group. This article discusses normal adolescent growth and development and provides strategies to support the normal growth and development.

Introduction

Thousands of ostomies are created in children and adolescents to relieve conditions such as inflammatory bowel disease (IBD), Hirschsprung's disease, colon atresia, imperforate anus, and pelvic and perineal tumors.[1] It is estimated that between 6% and 14% of all adolescents have symptoms of IBD, which encompass Crohn disease and ulcerative colitis.[2] As a result, the management of adolescents with ostomies presents multiple challenges for the WOC nurse. This article reviews the impact of ostomy surgery on normal adolescent growth and development and provides strategies to assist the WOC nurse in minimizing these potential growth and development alterations.

Adolescence: A Developmental Perspective

Defined as the period of life between childhood and adulthood, adolescence typically spans the ages of 12 to 18 years. It begins with sexual maturity and ends with the transition into young adulthood.[3] In Western countries, this period is referred to as the "teen years." The primary challenges of adolescence include comparatively rapid biological and sexual maturation, the development of personal identity, intimate sexual relationships with appropriate peers, and establishing independence and autonomy in the context of the social environment.

Biologically and sexually, adolescents move relatively quickly from childhood to physical maturity. Rapid growth in height occurs for girls between the ages of about 9.5 years and 14.5 years; these changes peak around 12 years of age. For boys, the period of most rapid growth typically occurs between the ages of 10.5 and 11 years and then again as they reach 16 to 18 years of age. Early prepubescent changes in girls begin with the appearance of secondary sexual characteristics such as breast buds and pubic hair in girls, while prepubescent changes in boys usually begin with testicular enlargement. Midadolescent changes include the onset of menarche and the development of a female habitus for girls, and spermarche with nocturnal emissions and voice changes for boys. For boys, late adolescent changes include ongoing growth in muscle bulk and body hair.

Because of the sudden physical changes adolescents experience, this developmental period is fraught with sensitivity and concern about one's body habitus, often resulting in overly critical comparison between self and one's peers. Since no set pattern exists for these sudden physical changes, adolescents tend to experience periods of awkwardness in terms of both appearance and physical ability.[3] In addition, considerable anxiety may arise if adolescents are not prepared for these sudden physical changes.

Psychological and social changes occur simultaneously during adolescence. Between the ages of 12 and 18 years, adolescents develop the ability to comprehend abstract content, moral philosophies, a personal identity, and

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sense of self. Concrete thinking begins with a progression of sexual identity (sexual orientation) and reassessment of body image. Adolescents tend to focus on the present. They are just beginning to think about experiences, analyze information, and make critical decisions about future choices and consequences.[3] Beginning at the age of 11 to 14 years, many adolescents are preoccupied with their own desires and needs and can be insensitive to others. Because of the self-centered focus, adolescents often think that people are watching them and they are being judged by an imaginary audience. This imaginary audience might be expressed as overly self-conscious and concerned about appearance; thus, adolescents might change their clothes often or are constantly checking in the mirror to see how they look. It is normal for adolescents to view themselves as "invincible," which can limit their ability to assess risky situations and future consequences. In late adolescence, abstract thinking is fully developed. With the ability to differentiate law and morality, adolescents can either reject or accept religious or political ideology. Healthcare providers should be aware of the adolescent's abstract thinking ability when seeking informed consent for treatment.[3]

Another part of the psychological development for adolescents is developing a sense of sexuality and body image. Body image is defined as a person's inner formation of his or her own physical appearance, which may or may not correlate with objective reality.[4] Each person holds an image of a physically perfect person in mind and evaluates his or her appearance against this ideal. An individual who is pleased with his or her body shape and appearance is said to have a positive body self-image. The psychological construct of body image includes cognitive and emotional aspects as well as sensory input.[4,5] For example, people modify their body image based upon their emotional state and the perceptions of others.

Because adolescents undergo comparatively rapid physical changes during puberty, perceptions of body image are heightened. These perceptions can be influenced by self and others and by societal standards of appearance and attractiveness. Given the overwhelming prevalence in Western society for the female image as thin and lean and for the male image as strong and lean, multiple concerns about body image are likely to occur.[6] Adolescent girls are vulnerable to forming a negative body image as they tend to ignore other abilities and focus solely on appearance.[4] The sole focus on appearance is viewed as evidence of worthiness. This view of worthiness often results in lower self-esteem and leads to increased risk for psychiatric disorders that are often displayed in eating disorders.

Adolescent culture is increasingly focused on the Internet. Computer access and use among adolescents have grown exponentially over the past decade; more than 80% of American adolescents between the ages of 12 and 17 years regularly use the Internet, and nearly half log on daily.[7] The Internet is a place where adolescent issues such as identity formation, sexuality, and self-worth can be explored in a virtual commuinity.[8] As a social context, the Internet enables adolescents to have multiple communication functions such as e-mail, instant messaging, chats, and blogs in which they can participate and co-construct their own environment.[9]

Intimate Sexual Relationships

The concept of human sexuality is larger than gender (male or female) or sexual activity. Instead, it is a complex construct that involves an individual's physical makeup and self-perceptions and how one feels about others within society.[10] Adolescent sexual development begins in the preteen years and continues into adulthood. Sexual development results in development of multiple secondary sexual characteristics. As these physical characteristics develop, the adolescents' ways of thinking, emotions, wants, and needs change. Relationships are sought that assist the individual's efforts to adapt to new stresses and needs and provide opportunities for self-clarification. Adolescents seek to share thought and feelings with those who are experiencing similar events. Nevertheless, it is important to remember that these feelings develop at different times for different adolescents.

Dating becomes increasingly important, and sexual activity is frequent.[11-13] Nationwide it is estimated that 34.2% of all 9th to 12th graders are sexually active.[14] Serious and intimate relationships, including sexual relationships, are most common. Experimentation with sexual orientation is common, and open communication about sexual orientation among parents, adolescents, and healthcare providers is an important part of healthy sexual development. The findings of several studies also suggest that adolescents are interested in knowing about the genetics of their diseases and associated fertility issues.[11-13]

Independence and Autonomy

A primary goal of adolescence is the separation of self from parents in preparation for the transition to independent adult. Relationships between children and their parents are transformed into more equal relationships and must be frequently renegotiated in view of the adolescent's need for increasing autonomy. This negotiation occurs smoothly for some, but significant conflicts may arise in other families. As a result, arguments between adolescents and their parents may develop and become emotionally charged. Simultaneously, the adolescent's peer group becomes more significant as their autonomy grows. This peer group becomes a place where the adolescent can talk about ideas and concerns and compare oneself to other adolescents. Through romantic friendships, dating, and experimentation, adolescents learn to express and receive intimate or sexual advances.

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According to Erickson,[15] adolescents search for their own identity and "try on" different identities. For example, they may try different clothing styles or act one way with friends and another way at home. Usually this role confusion is resolved by formation of a single identity; however, some adolescents never seem to find themselves. For some adolescents, role confusion is minimized as they adopt their parents' standards and values. In contrast, some adolescents may not adopt parental standards and values, and they may form an opinion that others, especially parents, cannot understand what they are experiencing. As a result, they may experience difficulty realizing how their behaviors impact themselves or others. Adolescent safety concerns stem from physical strength and agility development prior to the development of good decision-making skills. Also, adolescents have a strong desire for peer approval and thus fear rejection. The increased strength and agility coupled with the strong desire for peer approval are why some adolescents participate in a variety of risk-taking behaviors that are often displayed as rebellion toward authority.[16]

Body Image

Because adolescents tend to focus on physical bodily changes, body image is an important developmental concern, and an insult to the physical body tends to intensify these concerns. Visible signs of an ostomy include the stoma itself, the need to wear a pouching system, and the potential need to wear different clothing. All of these factors can interfere with the adolescents' perceptions of physical attractiveness and being viewed as different from their peers.

Perceptions of self and body image can also affect an adolescent's confidence when making and keeping friends or formation of intimate relationships.[17] Body image concerns may be verbally expressed via angry statements or nonverbally by ignoring the issues or denial that body image concerns exist. Comments such as "I don't want to go anyway" or "It doesn't matter whether I go or not" may indicate impaired self-perception or body image.

As the adolescent becomes more independent, the peer group becomes the primary social environment. Self-acceptance and peer acceptance are intensified by illness and management issues associated with an ostomy. For example, a chronic illness such as inflammatory bowel disease may cause the adolescent to spend greater amount of time away from peers. In addition, the adolescent with an ostomy often must wait until the underlying disorder has resolved and they become comfortable with their ostomy care and its management before moving forward with the challenges experienced by peers without an ostomy or associated chronic disease or disorder.

The adolescent with an ostomy often finds achieving independence from parents difficult to achieve because of the need for ongoing treatments, multiple hospitalizations, and surgeries that are perceived by the adolescent as being imposed by others.[18] Adolescents with an ostomy may temporarily regress to a more dependent state because of the need for parental assistance with transportation to the hospital and physician appointments, treatments, and medications. In turn, parents may be more resistant to an adolescent attempting to gain independence, while coping with an ostomy and associated disorder. These factors may result in conflict between the adolescents and parents. It is not uncommon for adolescents to remain quiet during ostomy education when parents are present or for the parents to monopolize the conversation. Adolescents may voice their frustration with comments such as "I don't know, ask Mom" or "Mom takes care of that."

Adolescents with ostomies tend to perceive the past differently, and they may idealize memories of life prior to creation of a stoma.[18] For example, they may carry photographs or talk about themselves in relationship to "before my illness or that was before my ostomy." For some adolescents, the illness managing the ostomy and associated disorder may literally consume their lives and the focus becomes the medical schedule with numerous appointments, treatments, and various medications.[18] Because adolescents often do not plan ahead well, healthcare concerns or problems may be minimized until immediate action is needed. For example, clinical experience reveals that many adolescents will wait too long between pouch changes, develop peristomal complications from inadequate cleaning, or not report status changes simply because they were not thinking about the consequences. In other cases, the desire to be "normal" is so strong that it may motivate the adolescent to avoid or delay important disease management behaviors especially when they are with friends.[19]

The most significant sexual concern for adolescents is the physical changes associated with puberty including attractiveness, body size, and maturational rate. Chronic diseases may impair or delay the development of puberty.[19] Adolescents with chronic conditions tend to be more socially isolated than their peers and have limited opportunities for psychosexual development, which can lead to feelings of depression, anxiety, and low self-esteem.[16,20]

In an effort to achieve normalcy, an adolescent with a chronic condition may engage in sexual activity before he or she is emotionally ready.[12] Suris and colleagues[11] reported that 45% of youths with visible conditions such as cerebral palsy, muscular dystrophy, and arthritis and 39% of youths with nonvisible conditions such as diabetes mellitus, asthma, and seizure disorders reported having intercourse between 13.2 and 14.1 years of age. Males and females with chronic health conditions were more likely to report having had a sexually transmitted infection than age-matched controls. In addition, adolescents with chronic health conditions and disabilities are more than twice as likely to report a history of physical or sexual abuse.[12,21]

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Implications for the WOC Nurse

Because growth and development varies, it is important that the WOC nurse recognize each adolescent and family as different. When talking with adolescents, it is critical that the WOC nurse use positive communication strategies in order to promote trust. One of the most important communication strategies is listening. When working with adolescents, learn to listen twice as much as one speaks. If the adolescent has something to share, simply taking time to listen promotes trust and acceptance. It is important to accept all of feelings portrayed by the adolescent provided they are shared respectfully. Adolescents will share their thoughts and feelings if they believe that the listener truly cares.[22] When offering constructive criticism, focus on what was done correctly before offering constructive criticism. In contrast, lecturing or talking "at the teenager" tends to convey an impression of superiority that does not promote development of trust between the adolescent and the WOC nurse. In addition, shared information must be kept confidential as adolescents may not risk offering any intimate thoughts or feelings especially if they believe that trust has been or will be breached. I also recommend refraining from multiple direct questions when counseling with adolescents that can create an impression of interrogation rather than conversation.

Promote Positive Body Image

The WOC nurse should encourage adolescents to share concerns related to their body and how their physical appearance might be affected by their illness or treatment. Sharing information about anticipated physical effects of medications and treatment may also encourage discussion. Using questions such as "Other teens have asked about… Is that something that you are wondering about?" or "Other teens have shared with me that… Is that something you are wondering about?" encourages the adolescent to express concerns and fears that have been expressed by others in their age group.

Another strategy to promote communication with an adolescent patient living with an ostomy is to encourage the person to participate in treatment decisions as much as possible such as stoma siting, and pouching selection. Other discussions may include handling anticipated events such as dating, dances, and overnight stays. Encourage the adolescent to engage in discussions regarding unanticipated events, such as pouch leakage, becoming ill, or having no appliances. These discussions help prepare the adolescent to manage successfully these situations which might otherwise cause frustration and challenge their body image.

It is important for the WOC nurse to promote socialization as much as possible. Role-playing situations such as what to share with friends and family can provide the adolescent with a safe venue to perfect their responses. Once the adolescent is comfortable in talking with their peers, the WOC nurse should encourage the individual to spend as much time with friends as possible. Whenever feasible, connecting adolescents with others living with an ostomy can provide peer-to-peer support. The ostomy support group or attendance at an ostomy Youth Rally Camp also provides opportunities for adolescents to interact with peers. Since the adolescent's social environment is increasingly expressed via Internet connectivity, providing adolescent specific ostomy Web site resources as shown in Tables 1 and 2 is also recommended.[8]

Teaching self-care skills related to the ostomy such as frequency of scheduled pouch changes, monitoring for stomal and peristomal complications, and troubleshooting promote self-care and autonomy. The WOC nurse can assist adolescents in learning coping strategies by sharing coping strategies from other healthcare providers or from other adolescents with similar conditions. Collaboration with the school and school nurse to devise a plan for self-care during school hours and activities also promotes independence.

Knowing that adolescents may wait too long to drain a pouch or change a pouch, the WOC nurse can proactively help set routine appliance change schedule that works well with the adolescent activities. The WOC nurse can assist with establishing a set plan of ordering of supplies and assisting the adolescent in planning ahead by preparing traveling or overnight packs so that they are ready when the need arises. During follow-up visits, the WOC nurse should inquire about upcoming activities and plans for handling these activities. Based upon the adolescent responses, the WOC nurse can offer either alternative suggestions or positive encouragement for handling the stated activities.

Healthy expression of sexuality is also encouraged by open communication about these issues. The WOC nurse can create opportunities to talk about sexual concerns with questions like "Other teens have asked about how to handle dating with an ostomy or kissing someone with an ostomy? Is that something that you are concerned about?" These types of questions keep both anxiety and tension to a minimum and promote a trusting environment. Adolescents may have differing views on sexual matters from the WOC nurse. These differing viewpoints stem from the adolescent's maturing cognitive skills, reasoning ability, and propensity toward considering differing viewpoints and possibilities. When differing viewpoints arise, it is important to talk with adolescents calmly and firmly to prevent expressed differences from becoming battles.

Because the presence of an ostomy and the associated illness often strains coping mechanisms, the WOC nurse can teach and encourage problem-solving skills by asking "What if" questions. Such questions are helpful because they allow adolescents to practice responses in a safe and secure environment. Infusing gentle and appropriate humor when discussing, "What if" happenings is helpful

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TABLE 1.

Online Resources for Adolescents Living With an Ostomy

Name	Web Site Address	Content
Intestinal Disease Education and Awareness Society	http://www.ideas-na.com	Canadian nonprofit organization devoted to awareness of gastrointestinal disease
		Sponsors camps and youth rallies for adolescents with bowel disease and ostomies
Lance Armstrong Foundation	http://www.livestrong.com/ostomies/	Offers multitude of different links for different ostomies
		Many adolescents will identify with the Lance Armstrong campaign as many adolescents wear the Lance Armstrong "Live Strong" bracelet
Crohn's and Colitis Foundation of America (CCFA)	http://www.ccfa.org/ click on "kids and teens" link	Nonprofit, volunteer-driven organization dedicated to finding a cure for Crohn disease and ulcerative colitis
		Several links available including one specifically for "kids and teens" containing information on camps, parenting, going to college, and other resources
Sponsored by CCFA and Starlight Foundation	http://www.ucandchrons.org/ Facebook app Free site Teens must log on and register	Listed on the CCFA Web site under resources for "kids and teens"
		Practical advice for teens on how to deal with illness, survive in school, talking with doctors, and other topics of specific importance to teens
		Starlight World link, takes teens (between 13 and 20 years of age) or siblings who have serious, chronic, or life-threatening medical conditions to an online community (virtual hangout)
		Teens can build on existing relationships they might have formed with other teens through treatment or can connect with other experiencing the same things
		Moderated chat rooms, games, bulletin boards, videos, and other such avenues for the teens to share information
My Child has an Ostomy United Ostomy Association	http://www.uoaa.org/ostomy_info/ pubs/uoa_brochure_child_has.pdf	Two-page printable pamphlet
		Not directed specifically at the adolescent, but parents may find this helpful
Ostomy Guide	http://www.ostomyguide.com/useful-ostomy-supplies-for-pediatrics/	Offers latest information on a wide variety of ostomy topics
		Provides links and educational resources
		Though not specifically directed toward the adolescent, the adolescent may find it helpful
Children's Hospital of Boston	http://www.childrenshospital.org/…/ Site2577/Documents/Patient%20 Guide%20to%20Illeostomies.doc	Three-page downloadable easy reading handout with drawings, offers answers to common parent questions regarding ileostomies and colostomies
Emedicine from WebbMD	http://emedicine.medscape.com/ article/939455-overview	Quick overview of small and large intestinal stomas with good information and pictures
		Check updates as page not consistently updated
Coloplast	http://www.coloplast.com/ostomycare/ pages/ostomycare.aspx	Easy navigation and reading and offers a variety of information for children and parents. Nothing specific for adolescents
Supported by Hollister, Inc	http://www.c3life.com/ostomy/	Relatively a new Web site offering information and assisting to connect those with ostomies
		Link available to 6 clinicians to ask questions

as laughter can provide an emotional outlet that can diffuse any anxiety promoted by asking such questions.

Should the WOC nurse become aware of situations that require emergent medical interventions or extra medical interventions because the adolescent did not follow the prescribed medical regimen, discussion can be encouraged by asking questions such as "What did you learn from…?" It is not helpful to reprimand noncompliant behaviors as this strategy can create an authoritarian environment that can potentially limit rather promote open communication. Mental health services may be needed for adolescents who consistently do not follow medical regimens, who

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TABLE 2.

National Organizations

Crohn's and Colitis Foundation of America	800-932-2930 http://www.ccfa.org
Pull Thru Network	205-978-2930 http://www.pullthrunetwork.org
Reach Out for Youth with Ileitis and Colitis, Inc.	631-293-3102 http://www.reachoutforyouth.org
United Ostomy Association of America	800-826-0826 http://www.ostomy.org
Wound, Ostomy and Continence Nurses Society (WOCN)	888-224-WOCN (9626) http://www.wocn.org

exhibit signs of development regression, or who lose interest in age-appropriate activities.

Other Strategies to Promote Growth and Development

Following ostomy surgery, the WOC nurse can promote growth and development by providing anticipatory guidance to adolescents and their families. The WOC nurse can meet the adolescent and family to establish a relationship and exchange information about what to expect during surgery, postsurgery, and upon discharge.[23] This period also provides an opportunity to address questions and concerns including stoma siting to ensure that the needs of the adolescent are met.[24]

Adolescents and their families should be visited by the WOC nurse as soon after surgery as possible. During these encounters, the WOC nurse is in a prime position to intervene should patient status change or questions/concerns arise from the adolescent, parents, or bedside healthcare providers. Discharge planning should involve the adolescent's school, and the school nurse should be contacted to discuss transition plans. Because school nurses may be unfamiliar with ostomy products, the WOC nurse can serve as an adviser and consultant to this valuable ally.

Online and printed resources should be shared with the adolescent, family, and their primary healthcare providers. The Pediatric Ostomy Care Best Practices for Clinicians,[24] developed and released by the WOCN Society, is an excellent source for providing care for the child or adolescent with an ostomy. Table 1 lists online resources for information and support for adolescents and their families. Information about one of the multiple books written from both healthcare and patient perspectives is also recommended. Table 2 highlights national organizations available that are committed to the education, care, and research of diseases associated with ostomies, and to patients with ostomies of all ages.

Conclusion

When faced with an illness requiring an ostomy, an adolescent faces potential impairments in physical and psychosocial growth and development negatively affecting body image, socialization, independence, development of sexuality, and self-management. The WOC nurse must understand the impact of an ostomy on growth and development during the period of rapid changes and institute strategies to aid the adolescent to achieve physical and psychosocial milestones, while living with an ostomy.

KEY POINTS

✔ It is estimated that between 6% and 14% of all adolescents have symptoms of IBD, which may require ostomy surgery.

✔ The primary challenges of adolescences are biological and sexual maturation, the development of personal identity, the development of intimate sexual relationships with appropriate peers, and establishing independence and autonomy in the context of the social environment.

✔ The WOC nurse is ideally positioned to recognize these growth and development challenges and to institute strategies to promote adolescent growth and development.

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