people with a disability or chronic health condition

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Abstract

For a number of reasons, children and youth with a disability or chronic health condition are at an increased risk of sexual abuse. Health care providers, along with parents and caregivers, need to maintain a high level of suspicion concerning possible sexual abuse of this population. Physicians especially need to advocate for policies to prevent or detect abuse in hospitals, schools, and other institutional settings. Such policies include the thorough screening and monitoring of employees and volunteers; chaperoning physical examinations and treatment procedures; supervised outings; and ensuring an institutional culture that promotes patient privacy. In addition, physicians should promote patient self-awareness and empowerment, and provide early anticipatory guidance concerning sexuality, personal empowerment and abuse risks. The present document replaces the previous Canadian Paediatric Society position statement published in 1997.

Key Words: Adolescent; Sexual abuse; Prevention; Disability; Chronic condition; Sexual health

There is clear evidence that young people with a disability or serious chronic condition are at increased risk of being sexually abused. A large British Columbia survey of high school students in 2008 showed that students who reported having a limiting health condition or a disability were more than two times as likely as their peers to report having been physically abused (31% versus 15%) or sexually abused (19% versus 7%), and were three times more likely to have experienced both physical and sexual abuse (12% versus 4%). American and international data reveal similar numbers. It appears that this population is also at increased risk of being both physically and emotionally abused. This statement reviews common contributing factors to sexual abuse in this population, and the role that paediatricians can play in preventing, identifying, and dealing with abuse. It replaces the previous Canadian Paediatric Society position statement published in 1997.

Factors increasing the risk of abuse

All too frequently, young people with disabling conditions are placed in settings or situations where they are dependent on the unsupervised care of others: in schools, institutions or at home. Some societal factors and the lack of appropriate care facilities or support for these young people may add to their disease or disability-specific characteristics to increase the risk of abuse.

Societal factors

Youth with a physical/developmental disability or a chronic condition often have little control over decisions directly affecting them, particularly those relating to health care and education. This lack of control over basic aspects of life has the effect of confirming—for both the potential victim and the potential abuser—that persons with a disability or chronic condition are externally controlled, and therefore helpless to stop abuse or maltreatment. Along with this perceived disempowerment may be a reluctance by responsible individuals and institutions to hear what abused adolescents have to say. Young persons with a disability may grow up with the sense that their body is controlled, even ‘owned,’ by others. If abuse occurs, they are more likely to perceive it as a continuation of how they are usually treated.
For many ill and disabled young people, the social isolation caused by institutionalization, hospitalization, ‘special’ education and/or overprotection by families can push them to the margins of society, where they are more vulnerable to predators, often with little chance of detection.

In many (though not all) cultures, people with a visible disability are often viewed negatively. Cultural prejudice can foster feelings of superiority, unease and pity in non-disabled individuals, as well as feelings of being ‘flawed’ or ‘bad’ in young people living with a disability or chronic illness. Social stigma can lead young victims to believe that their mistreatment or abuse is somehow deserved, and so should not be resisted or reported [4]. In addition, adolescents with a disability are sometimes seen as asexual beings, not as potential targets for abusers, and may not be believed when disclosing abuse. Conversely, they can also be viewed as promiscuous or hypersexual, and therefore as partially responsible for experienced abuse.

Young people with a disability or serious chronic illness regularly encounter barriers to freedom of movement, self-expression and privacy that both increase the risk of sexual abuse or assault and decrease the likelihood of such incidents being reported.

Educational factors
Lack of sexual health education plays a significant role in abuse of this population. All too often, youth with chronic conditions receive less formal sexual health education than their peers, usually because they are misperceived as asexual or as less capable of understanding sexuality. Sex education is not prioritized because having a sex life is viewed as a ‘luxury’ that persons with a disability cannot fully experience. Being absent from health education classes due to hospitalization or frequent medical appointments can also contribute to the lack of appropriate sexual health knowledge in this population. Moreover, the availability of appropriate educational materials is often limited. Without education, these young people may even lack the terminology needed to report an abusive situation.

Health care factors
For people with a disability or chronic condition, tolerating and expecting a low level of privacy and a high degree of physical intrusion are ways of life [5]. If they have been forcibly restrained while resisting intrusive physical examinations or attentions to bodily needs, they may also have learned not to struggle or protest. When regular procedures are performed in demeaning or insensitive ways, children are more likely to tolerate abuse.

Disability-specific factors
Some adolescents with chronic conditions are particularly vulnerable as a result of cognitive, sensory, or mobility impairments, or difficulty communicating. A chronically ill youth with generalized weakness, for example, will have difficulty fighting off an attacker. Someone with mobility problems is less able to escape attack. Other limitations, such as speech and language difficulties, impede the ability to call for help, to resist an abuser verbally, and later, perhaps, to report abuse. An intellectual disability increases vulnerability to emotional manipulation or coercion.

Recognizing abuse
Parents, caregivers and health care providers need to maintain a high level of suspicion concerning sexual abuse when working with this population. Patients who present with sexually transmitted diseases, vaginal or anal trauma, unexplained urinary tract infections—even if they report consensual sexual activity—should be questioned carefully, using the patient’s preferred method of communication (e.g. American sign language [ASL] or Bliss). Other less specific indicators associated with abuse are: an unexplained fear of physical or gynecologic examination; the avoidance of specific caregivers or caregiving situations; self-harming behaviours; sleep disturbances; encopresis; sexualized behaviour; sexual experimentation with age-inappropriate partners; sexually abusive behaviour toward others; running away; and somatic complaints with no organic cause [5].

Disclosure
Although it is not the role of the physician to conduct an abuse investigation, creating a safe environment that is conducive to open communication is an essential part of the doctor-patient relationship. Open communication is more likely to invite disclosure of abuse. As for all adolescents, a first visit should clearly establish the limits of doctor-patient confidentiality. Physicians need to appreciate their patient’s developmental capacity to understand mandatory reporting, and be ready to explain this obligation in a clear and supportive manner. They must be alert and sensitive to the positive feelings
the patient may have toward an abuser. To ease the process of disclosure, questioning should be conducted using the patient’s preferred communication method.

Augmentative and alternative communication methods do not always provide access to a sexual vocabulary, though such resources do exist. For patients with a communication disorder, it may be difficult to find a skilled interpreter who is also trained or experienced in sexual abuse issues. In underserved communities, physicians can help to create or promote local training programs for interpreters who wish to qualify in this area. The Augmentative Communication Community Partnerships Canada (ACCPC) website has an extensive collection of resources on sexuality.

The formal process of disclosure must conform to legal and reporting standards. However, a New Zealand study showed that police officers were not only more likely to disbelieve women with intellectual disabilities when they reported abuse but also to perceive them as promiscuous. Following up with the disclosing patient after referral to appropriate authorities provides support through a confusing, challenging time. If the physician knows of individuals who understand both disability and abuse issues, a patient who has experienced abuse can be referred to them for counseling.

Prevention

Institutional
Physicians should advocate for institutional policies to prevent abuse, including:

- thorough screening and monitoring of employees and volunteers;
- chaperoning of physical examinations and procedures;
- supervised outings;
- an institutional culture that promotes patient privacy; and
- being alert to, and having procedures for reporting, symptoms/allegations of sexual abuse.

In addition, parents should be encouraged to inquire about institutional policies themselves, and to be especially vigilant when hiring private caregivers. Those working with teens with special health care needs should undergo intensive screening and be trained to understand the full range of normal sexual activity (including masturbation) for this age group. They should know when and how to respect the privacy requirements of adolescents.

Physician involvement in developing educational resources on abuse issues can reinforce preventive training at an institutional level.

Educational
Adolescents with a disability or chronic health condition, parents and other caregivers need appropriate information about sexuality, and should receive it. Information and resources specific to different developmental levels and disabilities on personal rights, safer sex, and sexual abuse, could also include a component on assertiveness training and self-defense. Sexual health education need not focus primarily on the negative: Physicians should develop a list of resources to help parents recognize their child’s healthy sexual self-expression as well as addressing vulnerability to abuse.

Health care providers
Respect for privacy during any physical examination is imperative, even at a young age. Paediatricians and other health care providers have an excellent opportunity to demonstrate this respect by draping patients and offering to stop the examination if they feel uncomfortable. Attending physicians need to model sensitive, respectful physical examination techniques to trainees. Inform new patients that they can have a relative, friend or attendant stay with them during an examination. In addition, physicians can encourage adolescents with chronic conditions to take a more active role in decision-making by helping them feel less dependent and more involved in determining their own care. To achieve this, a balance between cooperation and personal autonomy needs to be established. Relying on rewards or ‘consequences’ for cooperating is unwise because it undermines a patient’s ability to recognize and resist abuse.

Conclusion
Paediatricians are ideally positioned to play a significant role in preventing the sexual abuse of children and youth with disabilities. Often, they already have a long-term relationship with patient and family, are equipped to detect and identify changes in behaviour or symptoms that are clues to abuse, and can sensitively question a patient or family member if abuse is suspected.
Recommendations

The Canadian Paediatric Society recommends that paediatricians, family physicians and other health care providers:

• Be aware of the risks of abuse in children and youth with a disability, chronic illness or other limiting health care need;
• Help to prevent abuse by ensuring that their respectful and empowering behaviours are a role model for patients, parents, trainees and colleagues;
• Provide early anticipatory guidance on sexuality, personal empowerment and abuse risks.
• Interact with schools or other community forums to ensure/enhance sexual health education;
• Advocate for institutional policies that prevent sexual abuse, and facilitate a quick intervention if abuse has occurred.

Additional resource

BC Children’s Hospital provides a number of guides for parents and professionals on sexuality and sexual abuse prevention. They can be accessed in the sexual health section of http://www.bcchildrens.ca/KidsTeens-Fam/A-ZPamphlets/R-SPamphlets.htm

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References


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