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Issues of care for hospitalized youth

INTRODUCTION

Knowledge of normal adolescent development is critical in planning health care delivery geared toward youth in a hospital setting. Comprehensive health care also requires a clear understanding of the legal and ethical issues that affect the adolescent population. This statement reviews the concepts of providing developmentally appropriate care for youth when they are admitted into a hospital setting. In accordance with the World Health Organization and the Canadian Paediatric Society, an adolescent is roughly defined as an individual between 10 and 19 years of age (1).

There are little Canadian data on the rates of hospitalization in teens, but approximately 4.5% of hospital admissions in Canada are teens (2). The majority of admissions occur in otherwise healthy teens, are related to acute illness and injury, and are of short (usually a few days) duration. In specialized paediatric hospitals, it is likely that a significant percentage of admissions are of longer duration and occur in teens with a chronic medical condition; however, exact numbers are not available. A British study (3) reported that admissions increase between 12 and 19 years of age for adolescent girls – however, not for teen boys – reflecting increased admissions related to pregnancy and childbirth.

A BRIEF OVERVIEW OF NORMAL ADOLESCENT DEVELOPMENT

Puberty represents a time of rapid physical, cognitive, psychological and social change. The physical changes of puberty include rapid linear growth and progressive maturation of secondary sexual characteristics leading to reproductive capability. Cognitive developments result in the teen having far more sophisticated thought processes, allowing him or her to have increasingly adult decision-making and judgement. The older teen develops more mature and stable coping mechanisms, allowing them to better deal with the challenges of higher education or the work force, and mature relationships. Social changes include the teen becoming increasingly independent from parents for financial and emotional support, and guidance. Despite what is commonly thought to be a stormy time of life, this process of 'growing up' is relatively smooth and without major emotional or relationship turmoil for the majority of teens (4,5).

Although the developmental tasks of adolescents remain similar in different cultures, it is known that cultural

background and family values can greatly influence the outward expression of these transitions (5). For example, in Aboriginal communities, the role of elders in the community can greatly affect the expression of defiance of family rules. Different cultures have different ages at which dating is acceptable, financial independence is expected or substance use is tolerated (if at all). Defining 'normal' adolescent development must, therefore, always take into account the culture in which a youth has been raised, and what the norms are for that group (5).

Having a chronic illness can impact many of these expected developmental tasks of adolescence (6-9). The physical changes of puberty can be delayed or precocious in many adolescents with chronic illnesses; thus, they may appear younger or older than their chronological age. The normal psychological and social changes are often delayed in youth with chronic illnesses, due in part to a reduction in developmentally normal activities, including school, sports and socializing. Separation from the family is often delayed because of practical issues, including the need for increased care giving and financial need. Not uncommonly, a discrepancy between the physical and emotional development exists, and can be a great source of stress for the teen because people around them may treat them in an age-inappropriate way.

THE IMPACT OF HOSPITALIZATION ON TEENS

Teens face many challenges when they require hospitalization (10). Central to the challenge is the loss of control they experience in almost all areas of their lives during hospitalization. This loss of control may leave teens with feelings of anxiety, powerlessness, overdependence, helplessness and loss of independence (11). As opposed to younger children who readily accept the decisions of parents and other authority figures, teens are at a phase in their lives where it is normal for them to question their elders because they are striving for control over their own lives. During hospitalization, teens may lose the ability to decide even the most basic aspects of their day – when they eat, sleep or use the bathroom. They lose control over their privacy at the time in their lives when self-consciousness is peaking (12,13). In some circumstances, they even lose control over their bodily functions, such as urination and defecation. This loss of control is troubling to many teens,

and they may respond to the situation in different ways, such as regressing to the more dependent state of a younger child. Other teens may actively defy the rules of the ward, thus creating conflict and power struggles between the teen and their caregivers (14). Teens can be labelled as 'non-compliant' for failing to easily follow the instructions of their health care providers. Teens may feel bothered by frequent examinations by different professionals (15,16).

Hospitalization presents a challenge to teens from all backgrounds, but teens from ethnic, religious or cultural minority groups may face different challenges. Little is known about how these teens feel about hospitalization, but it is possible that the above struggles are amplified because they are temporarily separated from their families and removed from their cultural supports. For Aboriginal teens in Canada, who may live on reserves or in regions remote from where they are hospitalized, being displaced from their community may be quite distressing.

LEGAL AND ETHICAL CONSIDERATIONS

Most ethical and legal considerations that arise during the teen years are related to issues of consent to treatment and confidentiality. Examples of common dilemmas include parents requesting to withhold information from their teen, teens asking to withhold information from their family, confidentiality around substance abuse or sexual activity, or refusal of treatment in the context of an eating disorder. Decision-making in these situations should be in accordance with the Health Care Consent Act, which clearly states that consent to medical treatment depends on the mental capacity, not the chronological age of the patient (17,18). Only the province of Quebec has a fixed age of consent of 14 years, below which the consent of a parent or guardian is required (17). In all other provinces, the capacity to accept or refuse treatment is dependant on the teen's ability to understand his or her condition and the options available to him or her. To be capable, the teen must understand and appreciate the risks and benefits of accepting or refusing treatment. More complex illnesses and treatments are harder to understand and, therefore, require a higher degree of competency to consent to treatment. Under most circumstances, capable teens will choose to involve their parents and family members in decision making, and physicians should encourage and support this collaboration. Teens may choose to have other important people in their lives involved in their care and decision making, such as a guidance counsellor, coach or close friend. Whenever possible and reasonable, these requests should be accommodated.

Confidentiality is a right for all competent persons; therefore, all competent teens have the right to keep their health status private from family members, including parents. Although most teens admitted to hospital are with a parent, teens should be interviewed alone for at least part of the assessment. This allows the physician to ask questions without the parent present, and also gives the teen a chance to ask questions they may not have wanted to ask in front of their parents. Teens may only feel free to disclose certain

pieces of information (such as sexual activity or substance use) without a parent present.

Physicians are obliged to disclose health-related information obtained from competent teens under certain circumstances related to the safety of the patient or others. The most common circumstances are those in which the young person discloses suicidal or homicidal intent, or discloses abuse or neglect of themselves or their siblings. Health care providers should, therefore, inform families and patients in a timely manner about the scope and limitations of confidentiality.

DESIGN OF SERVICES FOR THE HOSPITALIZED ADOLESCENT

Adolescents in Canada can be admitted to a variety of different units when hospitalization is required, depending on their age, diagnosis and where in the country they live. Teens often feel 'out of place' when hospitalized, because in most situations the ward is not dedicated to their age group. A British study (19) reported that 81% of teens admitted to an adult ward reported feeling out of place. Paediatric wards fared somewhat better, with only 53% describing this same feeling. There are few dedicated 'adolescent wards' currently in operation in Canada; thus, most teens are admitted to general paediatric wards or, in some academic centres, to subspecialty-specific units (such as an oncology or a surgical ward). Teens can also be admitted to adult wards in smaller communities and general hospitals. Some hospitals in Canada may impose arbitrary age cut-offs for where teens are hospitalized. These decisions are often made for practical reasons related to bed management and staffing issues, and may not take into account and address the best interests of the youth themselves.

There are limited data on the optimal setting for hospitalized teens, but the ideal, of course, is one in which the needs of the adolescent patient are viewed holistically. When adolescent patients are dispersed throughout different specialty wards in paediatric or general hospitals, there is a risk that some health problems, particularly related to the physical and psychological changes taking place during adolescence, may go unrecognized. Health effects related to risk-taking behaviours, such as sexually transmitted infections, smoking, and alcohol or drug abuse data are often neither recorded in the medical records nor addressed with youth admitted to these settings (20). In a survey (21) of adolescent patients admitted to a large general paediatric hospital, 66% of the adolescents surveyed were dissatisfied with the hospital atmosphere and 87% were critical of the physical facilities. When teens are surveyed about their perspectives of hospitalization, the most frequent and pervasive complaint is around issues of lack of privacy. Teens report great discomfort in a ward environment with regard to certain activities of daily living including bathing, using the toilet, dressing and grooming. Even receiving treatments – such as physiotherapy – in a public place can cause self-consciousness for the hospitalized teen (12,13,22). Other frequently cited complaints include having a much younger

roommate, lack of privacy to talk on the telephone and having no access to a separate teen space (19).

Many authors endorse dedicated adolescent units as a superior setting for teens requiring admission (3,23-27). Such units have the potential advantages of addressing the complexity of the medical, mental health and social needs of the teen; grouping adolescents together to allow for peer support activities and creating a more 'therapeutic' environment. Dedicated wards can have health care providers who are appropriately trained and experienced in adolescent health, and the physical structure of the ward can be better designed to reflect the developmental needs of youth. Dedicated units also provide an excellent environment for training, education and research. Separate adolescent units are not a realistic option for most Canadian hospitals; however, a multidisciplinary approach involving interested and trained professionals from a variety of backgrounds (such as medical, nursing, mental health and child life) is feasible virtually everywhere.

CONCLUSIONS AND RECOMMENDATIONS

Hospitalized adolescents have particular needs that differ from those of other patients, based on their specific developmental needs. Regardless of the location of admission, the reason for hospitalization or the cognitive ability of the adolescent, the teen requires care by professionals with knowledge, experience and interest in the complicated needs of adolescents. The Canadian Paediatric Society suggests the following issues be considered for all hospitalized teens:

Location

Teenagers should be admitted to wards that routinely admit teens or, where available, dedicated adolescent units. Arbitrary age cut-offs should be avoided, so that teens can be admitted where staff are most familiar with the needs of youth and the conditions that bring them into hospital. The physical space should include youth-dedicated spaces that allow for recreational activities and socialization with visitors and other patients. Whenever possible, teens should be roommates with other teens.

Privacy

The physical space should be designed to reflect the teenager's need for privacy, including privacy curtains and areas available for confidential interviewing and physical examinations. All staff should be trained to understand and respect the privacy needs of youth. Consideration should be given to having a chaperone present when physical examinations are performed, particularly when performing genital and breast examinations, or when the physician is the opposite sex to the patient.

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Education

There should be access to educational programs to support the continuation of normal school activities while in hospital when appropriate.

Socialization

Opportunities for hospitalized teens to socialize with peers from home is important, and should be accommodated by allowing the teen time and space to see friends. Where possible, recreational group activities for teens in the hospital should be arranged by the staff.

Cultural issues

Special attention needs to be paid to the needs of hospitalized youth who come from a minority cultural background. Staff should have appropriate training on cultural issues so that the needs of these youth and their families can be holistically addressed. Interpreters should be available to help teens and their families who do not speak the same language as their caregivers, and the teens should not be put in the position of translating for their families.

Ethical and legal issues

Teenagers are capable of consenting to treatment unless the physician has cause to believe that the teen is not capable of understanding their condition or the treatments available to them. Confidentiality is a right for all teens capable of consenting to treatment. The physician should encourage open collaboration with parents and other caregivers in decision making. Teens should be given the opportunity to meet alone with their care providers to ask questions without parents in attendance.

Access to staff with adolescent health expertise

All staff working with teens should be knowledgeable about normal adolescent growth and development, and be familiar with the psychological impact of hospitalization on teens. Adolescent patients with complex needs should have access to trained adolescent health experts, such as adolescent medicine specialists, adolescent psychiatrists and nurses, social workers and child life workers with special skills, training and interest in adolescent health.

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The recommendations in this statement do not indicate an exclusive course of treatment or procedure to be followed. Variations, taking into account individual circumstances, may be appropriate. Internet addresses are current at time of publication