Demographic Changes

Did You Know?

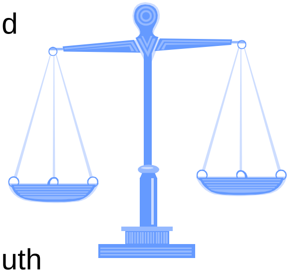
At present, 9% of youth ages 10- 14 years and 11% ages 15-24 have some disability due to a physical or mental health condition (Ministry of Supply & Services, 1992). As treatments for infants and young children continue to improve, these numbers will probably increase.

As well, between 1996 and 2011 the number of youth (ages 10-19 years) in B.C. is projected to increase by 16%, with over 64% of the growth occurring in the Greater Vancouver area.

While in general, the youth of B.C. have a high standard of health, approximately 7,000 youth are admitted to Vancouver hospitals annually with over 35,000 visits to out-patient facilities with majority being seen at B.C.'s Children's Hospital.

Adolescent patients account for 46% (ages 10-19) of the total number of patient's seen at B.C.'s Children's Hospital. In a one month period, over 1700 youth aged 11-20 years attended 47 sub-specialty clinics. On average, youth with chronic cognitive and physical conditions visit the clinics at a rate of 1.3 visits per year with approximately 1200 youth transferring to adult health care agencies annually. This predicted growth in the population of youth with chronic health conditions, coupled with the improved health status of this population, forces pediatric health care professionals to focus on the developmental issues of youth requiring ongoing care.

Government Policies/Laws Affecting Health Care For Youth



The recent changes in law and health care mandates in British Columbia should expedite the youth's access to age-appropriate health care. In 199I, the Royal Commission on Health Care 'Closer to Home' report recommended comprehensive, accessible health care for all with consultation with consumers and an emphasis on prevention. The Morton Report (1997) recommended that youth services include: the youth's needs, interests and future goals; help the youth establish networks of support for care and service; remove barriers to support services; and ensure a continuum of services for youth 16-18 years of age.

The **Canadian Consumers Association** produces a **Charter of Rights** (1974) declared that each individual has the right to:

- be informed
- participate in decision-making
- equal access to health care
- be respected
- confidentiality
- refuse treatment

The Infant's Act of 1994 takes these rights and legalises them for the adolescent population. The law removes the age of consent and contends that every individual has been given the right to consent or refuse his/her own health care provided that the individual is mentally competent to "understand the nature, consequences, risks and benefits of the proposed treatment".

The intent of the changed law is that youths' ability to give their own consent should increase their accessibility and utilisation of health care services and information. However, in order to make informed decisions they must have appropriate information and be guided through the process of accessing that information.

Availability Of Age-Appropriate Health Care

As the number of children surviving with chronic health conditions grows, the population of adolescents requiring care will also increase. Pediatric centers have traditionally given highest priority to program development for children two years and under (MacKenzie, 1990). It is not surprising to find that adolescents are the only group not to have enjoyed an improved health status over the past thirty years (Blum, 1987).

There is increasing consensus among adolescent-based health care providers that all young adults, when developmentally ready, should receive their health care in adult-oriented settings after being prepared for that transfer gradually and purposefully (Blum et al., 1993; Rosen, 1995; Schidlow & Fiel, 1989). The Council of University Teaching Hospitals Report (1995), under the title “The Role of Vancouver Hospitals in Meeting Youth Health Needs”, identified:

- the lack of age appropriate hospital programming for youth;
- the absence of effective transition mechanisms for youth transferring from pediatric to adult care in B.C.; and,
- the need of tertiary care centers to effectively interface with the community.

Recommendations included establishing policies and procedures which:

1. Demonstrate an appreciation of the adolescent’s need for autonomy and psychosocial sexual development.

2. Protect the privacy of youth and the confidential relationship with their health care providers.

3. Are specified for the adolescent age group.

4. Reflect the revised Infant’s Act , and Freedom of Information and Protection of Privacy Acts.

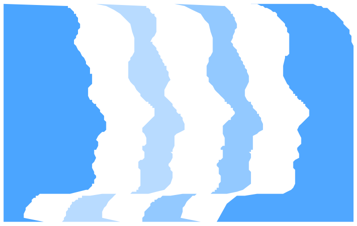
5. Project a youth-friendly attitude.

Just as the adolescent outgrows the parents and home, the needs of a maturing adolescent with a chronic condition will outgrow the expertise of pediatric specialists.

Youth, themselves, have expressed hopelessness when they remained in pediatric care long after their peers have left (Rettig & Athreya, 1991). Court (1993) completed a survey of 150 youth ages 15 through 18 years with insulin dependent diabetes mellitus. Of the 62% who responded, almost all suggested that transfer of care should be by 17 years of age. The COUTH Report (1995) recommended that BCCH, as the pediatric and youth tertiary centre for BC, should ensure that adolescents are transferred to the adult system by 18 years of age. It was also recommended that BCCH set up policies that at a minimum:

- co-ordinate meetings between the patient, pediatrician and adult specialist.
- ensure the family physician has continued contact throughout the transfer of care.
- ensure that referrals are made to appropriate resources in their own communities.
- recognize the developmental needs of the patient.
- offer the opportunities for involvement of multidisciplinary care providers.

Inconsistencies / Discontinuation in Health Care



The common factor amongst most youth with chronic health conditions is that they require assistance and monitoring from the health care system. Unfortunately, youth with chronic conditions have a tendency to reduce or discontinue their regular medical visits as they increase in age (Palfry, Levy & Gilbert, 1980).

Discontinuation of health care places the youth with chronic health care needs at risk of developing secondary illness or disability. Palfry et al. (1980) also found that 33% of the children and adolescents attending their sub-specialty clinics did not have a primary care physician and 38% had health problems they had never discussed with any physician or health care professional.

Caroll et al. (1983) found that 78% of the youth attending six different sub-specialty clinics named their specialist as their primary care physician, yet only 29% had discussed their general health concerns with this same physician. Researchers attribute this decline of regular medical care following discharge from pediatric centers to a lack of preparation and teaching about ongoing health care needs and the use of the adult system in meeting those needs (Kaufman, Terbock, Winters, Ito, Klosterman & Park, 1994). Young adults report that discontinuation of care is a result of limited practical support and information about available adult services, prior to leaving pediatric care (Thomas, Bax, Coombes, Goldson, Smyth & Whitman, 1985).

Differences Between Pediatric and Adult Health Systems

Adult health care differs significantly from pediatric care by virtue of the type and level of support, decision-making, and consent processes, and the amount of family involvement (Stineman, 1989).

Youth and their families need to learn about the differences between the pediatric and adult health care cultures.

The philosophy of pediatric care is family-focused, relies on parental decisions, and prescribes care within the support of a multidisciplinary team (Rosen, 1995). Health care for the child is conceptualized within the context of the family where the family takes responsibility for compliance, consent, treatment, and daily care needs.

In direct contrast, the adult health care system is patient-focused and investigational; it expects autonomous, independent behaviors, and expects informed consent from the young adult (Rosen, 1995).

Youth with chronic conditions need to be taught about the differences between the two care cultures and the behaviors that are expected of them as adult patients (Bronheim et al., 1988). Stineman (1989) illustrated the importance of teaching youth about the expectations of the adult system from her own personal experiences: “In broad terms the adult seeks care, the child receives care. The developmentally immature adult in the adult system of care is a victim since he or she is assumed autonomous” (p.11).

Influences of Current Health Care Practices

The health care system is constantly in a state of fluctuation. Restrictions of government funding for health care leaves the consumer extremely vulnerable to extended waiting periods for appointments, while health care providers face shortened visit times allotted to each patient, and reductions in staff. Recent initiatives of the BC Ministry of Health (1994) indicate that government policy will encourage primary care to shift to the community while specialized care for youth with complex, chronic conditions will remain at tertiary care centers. These are significant issues for youth with chronic health conditions who require specialized care from tertiary care centers but will also need to develop ties with their community health care services and professionals.

The general practitioner who has developed a relationship with the family and the adolescent is an essential link to the community (Kelly, 1995). The pediatric sub-specialty team needs to be aware of the primary care professionals and the community resources available in order to support the adolescents initiatives for local health care.

Families of adolescents with complex medical and social needs experience frustration with the fragmentation of health care services and require assistance in access to and co-ordination of appropriate services.

Youth deal with their chronic health conditions within the context of their families and health care services. The health care professionals in the sub-speciality pediatric teams can influence the adolescents development of communication, negotiation and decision-making skills through practice during the clinic visit. These skills can be role-modelled by the health care providers during the clinic visit and families should be encouraged to provide opportunities for their youth to practice these skills at home or in any social setting where decisions are being made. Schubiner and Eggly (1995) reviewed studies that linked improved health outcomes with clinical communication styles that encouraged greater patient participation. Communication styles that encouraged active participation by the patient included asking for understanding, problem-solving, and posing hypothetical situations. Youth have indicated that they expect health care professionals to provide confidentiality, privacy and informality (Ginsburg, Menapace & Slap, 1997).

> Communication strategies that foster understanding and partnerships between adolescents, families and health care providers will contribute to the development of a healthy transition for adolescents into adulthood and the adult health care system.

Moving Towards Transition Planning

Pediatric sub-speciality team members who have provided care and treatment to the adolescent and family, often since birth, have established a relationship with the adolescent and a knowledge base of the adolescents physical, emotional and social past experiences.

During adolescence, discussions during the clinic visit should shift focus from the parents to the views, attitudes and experiences of the adolescent. Acknowledgement and recognition of the adolescents past and present experiences will create a partnership of care and encourage greater responsibility for health-promoting behaviors.

The integration of transition planning into the sub-speciality pediatric clinics can be facilitated by a plan that incorporates:

- illness management
- the developmental tasks of adolescence
- the roles of the adolescent
- family and health care team members
- the conditions under which transition planning will occur

Transition planning needs to be flexible to meet the unique physical and cognitive abilities of each individual and family. Care for the adolescent occurs within the pediatric clinic setting because of a need to manage and monitor the health condition. Support and encouragement initiated in the clinic needs to be continued in the home.

It is important to ensure that the process proceeds at the youth's pace to encourage acceptance and understanding.