FACULTY OF HEALTH
Department of Community Health and Social Work
Learning Disability Division

Dip HE (Nursing)
Learning Disability Branch

Adolescence and learning disability

Work Book
Adolescence and learning disability

Aim

To introduce the student to the problems faced by adolescents who have learning disabilities

Learning Outcomes

On completion of this work book, the student will be able to:

1. Discuss the changes that occur during adolescence
2. Identify the common problems encountered by the adolescent
3. Identify the additional problems that may be encountered by an adolescent who has a learning disability
4. Prepare an action plan to enable a family to deal with a major issue of adolescence for a person who has a learning disability

Introduction

Question – What do we mean by the term adolescence?

Until a few generations ago, the phenomenon of adolescence did not exist. In the late 19th century, working life began at twelve years of age, and the young person passed from childhood to adulthood in a short space of time.

In many present-day primitive societies, there is still no such period as adolescence. The transition from childhood to adulthood is marked by a ritual ceremony. Young people can literally wake up in the morning as a child and go to bed at night as an adult with only a ritual ceremony to mark the occasion.

In western societies, adolescence is seen as a distinct period in a person’s life. This phenomenon has come about because of the number of social and technological changes that have occurred during the last few generations. Technological advances have required prolonged schooling in order for new
generations to meet the challenges of new technology. Social changes such as laws against child labour and an increase in the uptake of further and higher education for all social classes has resulted in more young people prolonging their education and deferring the uptake of employment. Prolonged schooling has created an interval between physical maturity and the adoption of the roles that accompany the traditionally held views of adult status (roles such as employment; marriage; children etc.).

It was the recognition that these physical changes resulting from puberty had psychosocial implications that fuelled interest in this new phenomenon (Paton & Brown, 1991). Psychosocial implications included the young person being dependent upon their families for longer and a requirement on the part of young people to develop new social groups with people in similar circumstances.

**Defining Adolescence**

Kett (1977) noted that despite the fact that changes have been acknowledged, clearly defined formal boundaries between childhood, adolescence and adulthood are lacking. Paton & Brown (1991) suggest that defining adolescence is a complicated process because of its dynamic, variable nature. Definitions of adolescence depend not only on historical, social and cultural factors (adult status is culturally determined), but also on the adolescent’s own self-perception. The young person may feel like an adolescent in one situation (for example, while at school) and like an adult in another (for example, while holding down a part-time job).

The physical changes associated with this period are also variable and contrive to cloud the issue of the definition further. For example, the height spurt and genital development in both boys and girls may not occur at the same time (and is also varied among peers).

Paton & Brown (1991) note that:

> It is against the background of these dynamic physical and social changes that the person is faced with the major task of forging a sense of self. He or she is required to reconcile new social and intellectual abilities with the expectations that society has about making the transition from the dependency of childhood to the independence of adulthood.

Paton & Brown (1991, Page 104)

In Western society, adolescence is defined simply as “a period of transition between childhood and adulthood” (Paton & Brown, 1991, page 104). There are no specific age limits, but it is generally accepted that the onset of puberty represents the starting point and ends with the adoption of adult roles (as defined within a given society or culture).

The problem with this definition is that the onset of puberty is also difficult to define. According to Bouras (1994) girls have a single defining point of entry
into adolescence – the experience of menarche (the first appearance of menstruation). It could be argued however that pubescence in girls commences before menarche, with hormonal changes, developing breasts and pubic hair. Bouras (1994) also states that boys do not have a critical event, which defines the entry into adolescence. It can be seen therefore that the onset of adolescence and the point at which adolescence ends is very difficult to pinpoint.

What is Adolescence?

Adolescence is marked by puberty, a period of transition where our bodies come to sexual maturity. What actually triggers the start of puberty is unknown, but once started, the hypothalamus controls the changes by stimulating the pituitary gland to produce hormones or chemical messages that initiate the great changes. Adolescence is a roller-coaster time of changes, a time of storm, stress and emotional changes when biology takes control of behaviour. Even those who know what is going to happen can have no idea of how it will feel. There are the obvious physical changes but the most dramatic change is the upheaval of thoughts and emotions as ‘emerging adults’ struggle for independence. This struggle for independence is set against the parents’ need to protect their children.

Regardless of the level of ability, adolescence is associated with increasing size, strength and assertiveness.

During adolescence, the young person must:

- Come to terms with his or her physical appearance
- Develop to sexual maturity
- Establish a sense of identity as an individual
- Develop a value system
- Prepare to make many decisions which will affect the adult life (e.g. choosing an occupation)

Adolescence can be sub-divided into three phases:

<table>
<thead>
<tr>
<th>Stage of adolescence</th>
<th>Approximate age (in years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early</td>
<td>11 – 13</td>
</tr>
<tr>
<td>Middle</td>
<td>14 – 16</td>
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<tr>
<td>Late</td>
<td>17 – adult</td>
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Early Adolescence – During early adolescence, there is a rapid change in growth and physical appearance. Early adolescents need time to come to terms with these changes. However their ability to do so depends on issues such as early or late puberty – late puberty can cause embarrassment within peer groups for example, when changing for PE/Swimming etc.

During this period, young people are beginning to prepare themselves for independence. As this preparation takes place, the peer group
plays a more important role in promoting development. This however can lead to conflicts between adolescents and parents.

Middle Adolescence – During middle adolescence, experimentation with different roles and ideologies takes place. This may involve trying out risky or dangerous behaviours – people of this age crave excitement in a way that most adults find difficult to understand. The adolescent is trying out behaviour gleaned from parents or adult role members but will also want to conform to standards inherent within the peer group – experimentation with drugs or smoking usually takes place in the company of others. The peer group is particularly important in the middle phase and provides an important source of social support in a time of upheaval.

This phase is also associated with the development of interest in members of the opposite sex and developing complex social skills. The variation in rate at which these changes takes place however varies enormously.

Late Adolescence – During late adolescence, young people are faced with the task of attaining independence, developing intimate relationships and making decisions about their future. The nature of these choices influences the nature/degree of conflict. For example, prolonged dependence as a result of further/higher education results in more conflict between parents and adolescent.

During this phase, the peer group looses its central position and intimate relationships become more important.
Physical Characteristics of Puberty

Male

Enlarged external genitalia
Breast enlargement

Production of spermatozoa
Nocturnal emissions

Facial and chest hair
Larynx increases in size
Vocal Cords thicken
‘Adams Apple’

Female

9 Years old

- Increase in height and stature
  - Increase perspiration
  - Acne
  - Increased activity of sebaceous glands
  - Increased fat deposition

12 Years old

- Appearance of pubic hair

14 Years old

- Growth of auxiliary, perineal hair
  - Deepening of voice
  - Skeletal system grows faster than supporting muscles
    - Hands and feet grow proportionally faster than rest of body

18 Years old

Mature primary and sexual characteristics

20 Years old

Mature stature

Mature stature
Common Problems Encountered

Emotional Problems – Research shows that 40% of adolescents have felt so miserable that they have cried and have wanted to get away from everyone and everything. More than 20% of adolescents think so little of themselves that life does not seem worth living. These common feelings can produce a state of depression that may not be obvious to other people – recent research suggests that emotional disorders are often not recognised, even by family and friends.

Consider what you feel would indicate emotional distress. Answers could include: over eating, excessive sleepiness, a persistent over-concern with appearance, phobias or panic attacks. Problems with recognising signs of emotional distress occur as many of the signs noted above are observed in adolescents without emotional disorders.

Sexual Problems – The dramatic physical changes of adolescence can be very worrying to some adolescents, especially to those who are shy and don’t like to ask questions. The varying rate of growth and development may cause concern for many adolescents, particularly if adolescents are comparing their development with members of their peer group.

More than half will have had their first experience of penetrative sex before the age of 16 and so the fear and risk of pregnancy, HIV and AIDS are an important part of adolescent life.

Behaviour Problems – Adolescents and parents often complain about each other’s behaviour. Parents often feel they have lost any sort of control or influence over their child. Disagreements are common and are part of the young person’s struggle to forge a separate identity.

School Problems – Those who play truant from school are usually unhappy at home and frustrated at school, so spend their days with others who feel the same way. Emotional problems, such as worrying about oneself or about an issue at home will often make it difficult to concentrate and so affect schoolwork.

Pressure to do well and pass exams may come from parents or teachers, but adolescents usually want to do well and will push themselves. Excessive nagging can be counter-productive. Exams are important, but they should not be allowed to dominate life or to cause unhappiness.
**Trouble with the law** – Most young people do not break the law, and those that do are usually boys. When they do, it usually only happens once – repeated offending may reflect a family culture, but may also result from unhappiness or distress – so it is always worth asking about these feelings when an adolescent is repeatedly getting into trouble.

**Eating Problems** – A common cause of unhappiness is feeling fat. This is particularly true of young adolescent girls who when they begin to develop natural fatty deposits on hips, buttocks and inside thighs as a result of hormonal changes (increased oestrogen), often become concerned with their body image.

Overweight adolescents, who are criticised or made fun of maybe at home or at school or both, become depressed and grow to dislike themselves. This may lead to inactivity and comfort eating, which worsens the weight problem.

**Adolescence and Learning Disability**

According to Bouras (1994), studies of adolescents with learning disabilities are scarce. Bouras (1994) cites the following reasons for the paucity of studies on adolescence:

- It is a relatively short period
- Few practitioners are trained to work with adolescents
- Adolescence is a highly complex stage of development making studies very difficult
- Adolescents are difficult to deal with!

The changing provision of services may also have an impact on the lack of studies relating to adolescence and learning disability. Service provision prior to 18 years of age is generally supplied by education with input from community nurses as necessary. Adolescents with severe behaviour problems or severe health care needs may access adult settings, but this is rare before the age of 18. Transfer to adult services can mean a transfer to health service provision for those with health care needs.

During school years, people with learning disabilities and their families may have enjoyed the relative security of a comprehensive and co-ordinated child health service centred around the special school. Adolescence and puberty bring changes in a learning disabled person as in any other, and families have to find new ways of managing a child who is rapidly becoming an adult.

Generally, children without disabilities are able to discuss problems and changes occurring in adolescence with parents and peers, but people with leaning disabilities may not have the skills required to communicate such feelings.
Additional Problems of learning disabled adolescents

Communication problems – The learning disabled adolescent may not have the skills required to communicate feelings to parents and/or peers.

Emotional problems – Failure to interpret body changes as part of normal development may lead to fear and anxiety which may result in increased hyperactivity and behaviour disturbance. Loneliness, frustration and rejection may be the experience of a learning disabled person who is trying to come to terms with changes which are occurring in his or her body.

Inappropriate behaviour – Many of the more disabled adolescents show an exacerbation of difficult behaviour in the teenage years. Physiological changes leading to puberty and the increase in size can also produce psychological changes. Wing (1996) notes that even the most severely disabled adolescent who is unaware of social situations is still reluctant to accept adult authority and still displays a determination not to give in to adult authority. In those with limited ability, these feelings may be shown by a return to temper tantrums, aggression and other behaviours of early years.

This can create difficulties for carers in dealing with this, as the young person may be bigger and stronger and may well be aware of this fact. There are many cases of parents “giving in” to their adolescent children who end up with few life skills and not achieving their potential because of the fear of parents.

Other problems for carers may include the fact that immature and inappropriate behaviour in a teenager can also attract more adverse reactions in public than for a small child — inappropriate behaviour tends to be more tolerated in younger children than in adolescents.

Confrontations with a young person who has an autistic disorder are even less likely to produce useful results. One of the major problems in caring for this group is the deep resistance to change. This needs careful planning at home and school in order to ensure an organised, predictable day with appropriate structure, but which also takes into account the changes in age, interests and attitudes.

Cognitive development – When a sudden increase in physical stature is not accompanied by growth in cognitive ability and skills, it is brought home to parents that their child will soon be an adult with a learning disability as a permanent condition. Parents will require considerable support and understanding at this time from special schools, community nurses and social workers.

Social problems – Learning disabled adolescents usually demand increased social activities and the development of peer-group relationships. This
can bring conflict within families since non-disabled siblings may be enjoying social activities which the learning disabled young person is attracted.

The learning disabled person may envy an adolescent brother or sister who is beginning to enjoy social contacts, dresses fashionably and has the support of an active peer group. Adolescents with altered body image may display signs of anxiety or depression. Fashionable clothes may be difficult to wear when a wheelchair is necessary, or when callipers are required.

It is not uncommon for learning disabled adolescents to be dominated by (well meaning) parents who impose their own dress code on their children. For example “I don’t want her to look like a tart!!” It is not uncommon to see adolescents either dressed like an elderly person or very childishly

**Sibling Rivalry** – For brothers and sisters, a learning disabled sibling may emerge as an embarrassment to them as they try to cope with the demanding changes of their own adolescence. Many parents may find it difficult to cope with the emerging sibling rivalry at this time, and parents should be encouraged to give additional support to non-disabled adolescents to work through their own feelings adequately

**Leisure Activities** – Inappropriate behaviour can reduce when the individual is occupied. Teenagers with learning disabilities, as with all young adults, tend to lose interest in the childish activities they enjoyed when younger. Problems arise when those who are less able do not enjoy the activities of adults. Additional problems occur when the resources available to the less able are age inappropriate. It may be difficult to find constructive occupations and leisure opportunities that are interesting and enjoyable to the individual concerned.

**Question** – what problems have you encountered in finding constructive occupations and leisure opportunities?
Consider constructive occupations and leisure opportunities that are appropriate for the less-abled adolescent.

**Sexual Development** – Puberty is not necessarily delayed in adolescents with learning disabilities, but individuals may look younger than their chronological age. For those with Klinefelter’s Syndrome, there may be some psychological trauma due to unusual sexual characteristics at puberty. Testosterone Therapy at 11 or 12 years of age can aid the development of more normal sex characteristics, but not the problem of infertility.
Curiosity and interest in social aspects of sexual relationships requires more language and social understanding than is found in less-able teenagers with learning disabilities. Curiosity may lead to inappropriate touching, looking or even undressing other children.

How would you handle this?

There is also a question as to whether adolescents with learning disabilities should be taught how to masturbate to orgasm if they are showing signs of sexual arousal and do not seem to know how to obtain relief or whether they should be left to learn on their own, but stipulate rules (e.g. privacy).

Menstruation in girls begins within the same age range as with other girls. Most seem to accept this without much concern, but a routine for changing pads will need to be incorporated with the aim of teaching self care in this area. Many girls who have epilepsy can have an increase in the number of seizures either during ovulation or before menstruation. Behaviour may also be problematic before menstruation (PMT).

Some girls may talk too openly about menstruation and there may be a need to explain that these conversations need to be limited to family and close friends.

Rebellion – Problems of rebellion may arise in areas such as medication compliance. Many medications can cause weight gain and other undesirable side effects for the teenager. Rebellion may also occur in the use of special diets for example low phenalalenine diet for PKU (however this diet can be relaxed somewhat after 10 years of age). Limited cognitive understanding and communication problems may result in difficulties with providing a rationale for the treatment. Careful discussions will need to take place in order for compliance to be maintained.

Exploitation – Adolescents with learning disabilities may be more susceptible to exploitation from other adolescents – it is not uncommon to find a person with learning disabilities in youth gangs who carry out unlawful acts for their ‘friends’ in exchange for ‘acceptance’ into the gang.

Sexual exploitation may also be a worry for parents/carers of adolescents with learning disabilities.
Activity

Produce an action plan to enable a family to deal with one of the major issues families are concerned with as their children pass through adolescence. Highlight any problems that may be encountered in attempting to provide for the needs of adolescents who also have a learning disability

Feed back to the main group

References and Recommended Reading


