

## Personal Viewpoint

# School-to-work Transition for Adolescents with Epilepsy

KL YAM, CW LAM

### Abstract

Epilepsy is a common condition and employment concern is one of the most serious problems encountered. To enable a successful school-to-work transition for adolescents with epilepsy, effort should be directed to the adolescent himself, the teachers and school personnel, the parents and family members, the rehabilitation agencies, the employers and the public. Vocational assessment should include medical, neuropsychological and psychosocial aspects. Mode of service delivery should be flexible. To ensure an effective program, differences between adolescent and adult clients, including the presence of identity crisis, disposition to peer pressure and propensity towards experimentation, should be acknowledged. Local studies to identify the size of vocational problem in adolescents with epilepsy and the most effective mode of service delivery in this population are needed.

### Key words

Adolescent; Epilepsy; Vocational assessment

### Introduction

Epilepsy is a common problem affecting 0.5-2% of the population.<sup>1</sup> Among these individuals, employment concern is cited as the most serious problem apart from education and pressure from families.<sup>2</sup> In a local study conducted by Yau et al in 40 epileptic adults (aged over 16 years, free from physical and psychiatric symptoms, and had work experience) using convenience sampling among members of the Hong Kong Epilepsy Association, 30% were unemployed and 63% believed that epilepsy would affect their employment.<sup>2</sup>

In contrast to other physical disabilities, epilepsy is a *hidden* condition.<sup>3</sup> Individuals who suffer from epilepsy do not look differently from other normal individuals. Moreover epilepsy is not a registered disability in many countries including Hong Kong. Therefore despite repeated literature documentation of employment concerns for individuals with epilepsy, employers and the society at large are often unaware of the problem. The importance of career exploration and vocational counselling is even more underrated among adolescents with epilepsy. However a successful transition after secondary school into suitable employment may be the best groundwork for stable employment in later adult life.<sup>4</sup> Therefore specific programs targeted at adolescents with epilepsy should be considered.

Understanding factors leading to the employment problem is essential for designing an effective service. As in adults, factors other than severity of the epilepsy may contribute to the employment difficulties. These include neuropsychological deficits, psychosocial problems, academic underachievement, lack of information, and negative attitudes from families, employers and the public.<sup>3,5-8</sup> Therefore assessment and exploration of the abilities and limitations of the adolescent, individual or group counselling, improvement of social and communication skills, cultivation of a positive

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Department of Paediatrics & Adolescent Medicine, Alice Ho Miu Ling Nethersole Hospital, 11 Chuen On Road, Tai Po, N.T., Hong Kong, China

KL YAM (任嘉玲) MRCP, FHKCPaed, FHKAM(Paed)

Department of Rehabilitation Sciences, Hong Kong Polytechnic University, Hung Hom, Kowloon, Hong Kong, China

CW LAM (林智偉) PDOT, PhD

Correspondence to: Dr KL YAM

attitude, pre-vocational and vocational training, work accommodation and epilepsy education are some important strategies.

Working with the adolescent himself, with teachers and school personnel, with parents and family members, with rehabilitation agencies, with employers and the public are important.<sup>9</sup> Paediatricians should play a strategic and leading role in filling the service gap and enabling a successful school-to-work transition.

### Working With the Adolescent

As all other adolescents, career exploration should be an important and essential task for adolescents with epilepsy. Self-assessment and understanding of one's interests, values, priorities, skills, abilities, aptitudes, credentials, personality and career orientation should be the first step.<sup>10</sup> The adolescent should also identify his needs and possible source of job satisfaction. The awareness of these vocational interests and patterns of abilities may be achieved by group discussion, personal reflection or individual assessment. A number of assessment tools are available. Vocational interests may be tapped by Strong-Campbell Interest Inventory whereas the pattern of abilities by General Aptitude Test Battery, Wechsler Adult Intelligence Scale, Academic Achievement Testing or Halstead Impairment Index.<sup>9</sup> Evaluation of abilities may also base on work samples and job-tryouts.

To assess epilepsy-related limitations and restrictions, help from paediatricians should be enlisted. Epilepsy may take many forms and vary considerably in frequency and severity. In the majority, seizures can be completely controlled with appropriate therapy, which may include antiepileptic drug treatment and lifestyle modification. In the minority of cases where restrictions on particular types of employment are necessary, such decisions must be based on fair and individual assessments of both the demands of the work chosen and the person with epilepsy concerned.<sup>11</sup>

In the United States, the law prohibits anyone who has had a loss of consciousness of any sort from any cause

(including most patients with epilepsy) to pilot planes, to drive trucks, buses or school buses, to work as air traffic controllers, to work on the control panel of nuclear power plant, or to operate roller coasters or rides in amusement parks.<sup>12</sup> For less critical jobs, blank restriction is not recommended and assessment should be individualised.

A German group suggested five categories that can be used to evaluate the occupational suitability of individuals with epilepsy<sup>4</sup> (Table 1). Seizure frequencies were grouped into four categories: more than one seizure per month, three to eleven per year, no more than two per year, and seizure-free. However, in countries where work accommodation is available, such guideline is less relevant.

Moreover, complete description of seizure variables is often more helpful in job matching or designing work accommodation.<sup>4</sup> Presence or absence of warning aura, any identifiable triggers, predictability of seizure occurrence, the state of consciousness and behaviour during seizure, presence or absence of fall during seizure, behaviour and the time need to resume usual activity after seizure are helpful information. Last but not the least, the reliability of the individual to take medication or the ability to attend to the medical regimen is an important factor for consideration.

In Hong Kong, no specific legal restriction on job is present. However, the ability to drive is an important skill in job seeking and there are guidelines for determining the fitness for driving in people with epilepsy.<sup>13</sup> The general principle is in accordance with overseas requirement – if the individual has been seizure free for two years, irrespective of the presence or absence of medication, he can usually operate a private motor vehicle safely. However, the person should be reviewed by medical practitioner yearly for a period of at least five years. If the individual develops further seizure while on medication, he should stop driving at once until further evaluation. If the individual has been seizure free for two years while on medication, but seizure recurs while on a trial period instructed by the medical practitioner, he can drive safely one month after he has resumed his medication. If the medication is stopped by the individual, the decision as to whether it is safe for him to drive depends on assessment of the reliability of the

**Table 1** Epilepsy risk categories of the German Task Force<sup>4</sup>

"O"	No loss of consciousness; no loss of posture; control of own actions (seizures only with subjective symptoms)
"A"	No loss of consciousness; no loss of posture; impairment of ongoing activity
"B"	Impaired consciousness; interruption of ongoing activity; no loss of posture
"C"	No loss/loss of consciousness; loss of posture; interruption of ongoing activity
"D"	Impaired consciousness; no loss/loss of posture; actions not in accordance with demands of the situation

person in taking medication regularly. Only in exceptional cases should an individual with any seizure operate passenger transport vehicle or heavy commercial vehicle.

Moreover, paediatricians may provide specific advice for individuals with specific type of epilepsy. For example, individuals with photosensitive epilepsy may suffer from seizure when they work with visual display unit, especially if the flicker frequency of the monitor is 50 Hz rather than 60 Hz.<sup>14</sup> Some simple advice includes avoidance of sitting too close to the monitor, having adequate background light and scheduling periodic rest period.

Neuropsychological assessment has been found to predict job success in individuals with epilepsy and known brain injuries.<sup>9</sup> Signs for possible concern of neuropsychological deficits include difficulty with short-term memory, problems doing multiple tasks or efficiently performing at task in the presence of distracters, unexplained discrepancy between apparent ability and performance, visual field deficits, learning disability symptoms, problems with attention and concentration, and unilateral weakness or clumsiness. Areas of concern include sensory motor integrity, motor speed of dominant side, speed of information processing of selective stimuli, attention and concentration, memory (especially short-term memory and incidental memory), verbal ability, cognitive efficiency and flexibility, mastery of abstract language concepts, visual-spatial ability, executive function and compensatory skills. Commonly used neuropsychological test battery include Picture Arrangement, Digit Symbol Test, Concentration Endurance Test/d2, Stroop (Naming of color dots, Naming of color prints), Controlled Oral Word Association Test, Name Writing Preferred Hand Trail Making Test Par B and Purdue Pegboard Test (Preferred Hand and Both Hand Assembly).<sup>9</sup> Most psychological test taps on a particular function (e.g. the Concentration Endurance test/d2 taps on concentration, but does not detect visual-spatial problem) rather than a full range of neuropsychological function, therefore the choice of test should be based on the clinical suspicion. Since these tests should be administered by psychologist and are expensive, only those with signs for possible concerns should be considered for assessment.

Psychosocial assessment will address behavioural problems and social skill deficits associated with epilepsy.<sup>9</sup> Areas of concern include adjustment within family, information about epilepsy and seizure, satisfaction with medical care, peer and social support, significant life goals, additional significant conditions, internal psychological adjustment and adjustment to social network. Commonly

used assessment tools include Washington Psychosocial Seizure Inventory, Adolescent Psychosocial Seizure Inventory, Rosenberg Self-Esteem Scale and Coping Health Inventory for Children.<sup>9,15</sup>

In Hong Kong, detailed assessments on vocational interests, pattern of abilities, medical limitation, neuropsychological or psychosocial aspects are not routinely available to adolescents with epilepsy. Medical and neuropsychological assessment and advice are usually given upon request from the individual. Psychosocial assessment may be provided by social workers or non-government organisations when deemed necessary. Vocational assessment, counselling and guidance for individuals with disability are provided by the Vocational Training Council, but there is no specific assessment protocol for adolescents with epilepsy. Therefore there is a need for improvement in these areas. For the time being, adolescents may need to take a positive and proactive role.

## Working With Teachers and School Personnel

In the United States, individualised educational plan is designed to meet educational needs that cannot be met via the general school curriculum.<sup>9</sup> The plan may be modified to include goals that are not primarily academic but rather vocational and prevocational. For many adolescents that will graduate from secondary school in a short time, the inclusion of vocational training may be more beneficial than specialised academic intervention. Experience from Seattle showed that work exploration, work experience and access to structured employment opportunities are useful for adolescents with epilepsy.<sup>9</sup>

In Hong Kong, a formal individualised educational plan is not available to adolescents with disability, including those with epilepsy. However it would be very helpful if teachers can at least arouse the awareness of vocational consideration among their adolescent students. Group sessions can be organised so that the adolescents can explore their own values, priorities, personality and career orientation. Information on available community vocational resources should be highlighted because the local study by Yau et al showed that 15% of adults with epilepsy did not know what services were provided by the authority concerned.<sup>2</sup>

Since academic under-achievement is common among adolescents with epilepsy, teachers should be sensitive to the difficulties encountered by these students and be ready to provide accommodation. The Hong Kong Epilepsy

Association in collaboration with the Hong Kong Society for Rehabilitation Community Resource Network has recently published a pamphlet for schools in which the problems of these students are highlighted.<sup>16</sup> Teachers are encouraged to give extra time or individual tutorial for assisting these students if they miss classes due to their seizures. Increased understanding from teachers and other reasonable accommodation will be very helpful and encouraging for students who have attention and memory problem, or information processing speed problem related to their epilepsy or drugs. The cultivation of a life-long education attitude among adolescents (including those with epilepsy) is important so that further targeted vocational training or job-specific training after graduation from the regular secondary school will not be regarded as exceptional. Teachers are also at a strategic position to point out the other abilities, skills and strength that an adolescent possess in additional to his academic achievement.

Although accommodation may be needed, overprotection will be detrimental to the psychosocial development of adolescents and should be avoided.<sup>15</sup> Adolescents with epilepsy should not expect special privilege. They should have the same rights and responsibility as other fellow students.

Teachers and school personnel should familiarise themselves with the condition of epilepsy and the acute management of seizure.<sup>16</sup> Unlike other medical problems such as asthma or short-sightedness, there are still irrational myths about epilepsy among fellow students. Teacher can provide correct information about the condition and prevent stigmatisation of adolescents suffering from epilepsy. A caring, accepting and open environment is necessary for integration of people with disability (including those with epilepsy) into the school and into our society in future.

### **Working With Parents and Family Members**

A supportive family environment has been found to have positive effect on the social functioning of people suffering from epilepsy.<sup>15</sup> Parents need to understand the anxiety that is often present in the adolescent with epilepsy. Cultivation of a positive and proactive attitude in the adolescent will help him to face his challenges later in life.<sup>17</sup>

Parents and family members should be knowledgeable about epilepsy, and the social and vocational implications. Adolescent may need information and guidance on sports, swimming, cycling, lifestyles, alcohol, caffeine, driving, etc.<sup>12,18</sup> The ability for the adolescent to participate fully in

daily living will enlarge his social contacts, decrease the sense of social isolation and provide a chance to improve his relationship with peers. Over-protective parental attitude is common but it may hinder the development of social skills, social maturity, self-confidence and autonomy in the adolescent.<sup>15</sup> Parents should learn to accept their new role as their adolescent develops autonomy and independence. On the other hand, avoidance of over-protectiveness does not mean that the adolescent should be reckless. Parents need to teach the adolescent to take a balanced attitude towards risk taking.<sup>12</sup> This may be achieved by improving the self-management of his epilepsy. Education about adaptive behaviour that may promote seizure control should be given. For example, the adolescent should gradually take over the responsibility of his drug taking and learn about possible precipitating factors for his epilepsy.

With regard to vocational implications, parents are also important persons who can point out the strength of the adolescent, support him for further targeted vocational training and cultivate a positive attitude. Unrealistic expectations from the adolescent must be recognised and addressed.<sup>9</sup> At times of difficulty with job finding, support from family members is important.

### **Working with Rehabilitation Agencies**

All people with epilepsy should have equal opportunities to gain access to available health care, rehabilitation and vocational programmes, and social support services to gain maximum control over their disorder and to maximise their chances of employment.<sup>11</sup>

In Hong Kong, medical health care is readily available to people with epilepsy and is mainly provided by the government. On the other hand, rehabilitation and vocational programmes are provided both by government and non-government agencies. The Vocational Training Council provides vocational assessment and guidance. Vocational training is provided by Skill Centres of the Vocational Training Centre or by Employees Retraining Scheme. The Selective Placement Division of Labour Department provides work placement assistance. Although the local study by Yau et al showed that 48% of adults with epilepsy rated the services provided by these authorities as suboptimal, the Labour Department has recently published a very useful booklet on job-finding for people with disabilities.<sup>2,19</sup> Requirements and duties of specific jobs are listed in the booklet. There is also information on job finding, application and interviewing techniques, effective

communication and social skills with fellow workers, stress management, and skills for disclosure of disability to the employers.

For non-government organisation, the Hong Kong Epilepsy Association works in collaboration with the Community Rehabilitation Network to provide vocational rehabilitation and social support services.<sup>20</sup> A vocational training program specifically for people with epilepsy has been designed by an occupational therapist working in Community Rehabilitation Network in 1997.<sup>21</sup> The program consists of three sessions in which the individual learns to become aware of one's ability, limitation and expectation, learns about the misconception about work, understands the process of vocational rehabilitation, matches one's working ability and job requirement, knows about the community resources, and starts to formulate a concrete plan in getting a job. However the program is not run on a regular basis and is not specifically tailored for adolescents. Enlighten Hong Kong Limited and 兒 會 are some other non-government organisations providing support and counselling services.

### **Working with Employers and the Public**

In job seeking, selection and employment, people with epilepsy should enjoy the same rights as other workers. Legislation is present in some countries to protect individuals with epilepsy from discrimination in employment.<sup>11</sup> The presumption is that they have to be able to perform the essential functions of the job, or be able to do so with reasonable accommodation. They may require a medical examination after an offer of employment has been made and only if the examination is job-related, required of all employees and is consistent with the law. Although Equal Opportunities Legislation and Disability Discrimination Ordinance is in place in Hong Kong, the local study by Yau et al indicated that 43% of respondents had experience of being excluded from application of job on the basis of their epilepsy.<sup>2</sup> Moreover 41% of respondents experienced adverse reactions (such as salary reduction, request for self-resignation, and dismissal from job) from their employers after the respondents disclosed their epilepsy.<sup>2</sup> There is a need to increase education about the legislative requirement for non-discrimination against disability.

For some employers, they do not have the knowledge about how to support individuals with epilepsy at work. Advice on work accommodation will be invaluable. Procedural accommodation, physical modification at work

station, and use of adaptive or assistive technology are some of the possible means.<sup>4,22</sup> Job restructuring or procedural accommodation may include redistributing non-essential, marginal job function for some position to other employees. Examples include: reassigning part of a job that involve working in high places or driving to another worker; scheduling consistent regular work shifts instead of changing shifts for individuals whose seizure activity is exacerbated by inconsistent sleep patterns; allowing an employee to take an extended break or time off after they have had a seizure. Physical modification in workplace may include: putting shields/guards around pieces of machinery, carpeting over hard surfaces in work area, replacing flickering lights if such lights stimulate seizure activity; floor covering/matting; installing automatic cutoff switch. Assistive equipment (such as electronic cueing devices on watches, telepagers, other memory aids, computer software program, and palm top computers) is more commonly required for people with additional cognitive or physical limitations. Assistive technology does not necessary imply high technology and expensive equipment. An example is to give written rather than verbal instructions for people who experience memory loss as a side effect of their medication.

Besides employers, epilepsy is still being misunderstood by the general public.<sup>23</sup> Thus education on the nature of epilepsy for the public will be useful to correct any myths about the condition and avoid unnecessary stigmatisation. A number of pamphlets on the condition have been published by the Hong Kong Epilepsy Association and the Community Rehabilitation Network. The two organisations have also recently launched an educational program for the community.<sup>24,25</sup> Other efforts include publication of a special feature story in the newsletter of the Equal Opportunities Commission and the setting up of a website (Hong Kong Epilepsy Info-Net at [www.hkepilepsy.com](http://www.hkepilepsy.com)) on the internet.<sup>26</sup>

### **Special Consideration in Programs for Adolescents with Epilepsy**

In the design of programs for adolescents with epilepsy, attention should be paid to the some special nature of this group of clients. In addition to an increase in physical status, adolescence is a period where intense psychological adjustment takes place. Adolescents often have identity crisis in which they try to define themselves by exploring their abilities, interests and values in life.<sup>27</sup> They have to

decide how to behave and what to do in life. It is important to let the adolescents understand that their epilepsy should not dominate their life. The value of them as a person is not lessened by their epilepsy. Adolescents should be encouraged to discover what they can do rather than being overwhelmed by what they cannot do. Therefore exploration of the strength of the adolescents is essential to build up their self-esteem.

Adolescents are prone to peer pressure.<sup>27</sup> They are intensely aware of their external appearance and behaviour. Therefore developing a seizure in the school or in public will lead to great psychological burden and low self confidence in the adolescents with epilepsy. Education on factors that will improve their seizures will give them a sense of control over their illness. Forming peer support group may give them a chance to help and support each other.<sup>15</sup> Adolescents will also realise that they have the ability to help others rather than being dependent on others for help. Recreational group activities may be particularly appealing to adolescents.<sup>15</sup>

Another characteristic feature of the adolescent period is their propensity towards experimentation.<sup>27</sup> They may attempt to omit or modify their drug regime, to try alcohol or soft drugs, and to have irregular sleep and lifestyle. All these may lead to a worsening control of their epilepsy. It is important to provide education on the nature of epilepsy, the rationale of their drug treatment and lifestyle modification.

Several overseas studies on the employment issue for adolescents with epilepsy are available, and specific programs have been designed in the United States, United Kingdom, Ireland, Germany and Holland.<sup>4,8,9,15,28</sup> Similar studies or programs are currently not yet available in Hong Kong. It would be useful to perform studies to identify the size of problem in our local adolescents with epilepsy. Overseas programs may be modified to suit the local scenario and to cater for the cultural difference. Since there is a variety of program models, studies to identify the most cost-effective mode of service delivery will also be needed.

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