



COLLEGE OF FAMILY PHYSICIANS SINGAPORE

THE SINGAPORE FAMILY PHYSICIAN

PERMIT NO. MICA(P):206/12/2011

VOL 38(2) APRIL-JUNE 2012

UPDATE ON FUNCTION & DISABILITY IN PRIMARY CARE





Centre for Enabled Living is the one-stop centre that provides centralised information and referral services, administers various eldercare and disability schemes, and promotes understanding and acceptance of persons needing care* as integral members of an inclusive society.

**Persons needing care refer to frail seniors and persons with disabilities.*

Our Referral Services are categorised according to the different stages that a person goes through in his life.

For children aged 0 to 6

1. Early Intervention Programme for Infants & Children (EIPIIC)
2. Integrated Child Care Programme (ICCP)

For adolescents aged 7 to 16

1. Special Student Care Centres (SSCC)

For adults aged 17 to 55

1. Sheltered and Production Workshops
2. Day Activity Centres (DAC)
3. Residential Homes and Hostels

For seniors aged 56 and above

1. Assessment & Coordination for Enabling (ACE)
2. Day Care Centres
3. Home Help Services

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Permit No. MICA (P) 206/12/2011
JOURNAL OF THE SINGAPORE FAMILY PHYSICIAN
Printed by Tri-Art Printers Pte Ltd

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UPDATE ON FUNCTION AND DISABILITY IN CHILDREN AND ADULTS

A/Prof Goh Lee Gan

SFP2012; 38(2): 3

This edition of the Singapore Family Physician is an update of the issue in 2007 on function and disability in children and adults. Thanks are due to Centre for Enabled Living (CEL), Ministry of Health (MOH), and Ministry of Community Youth and Sports (MCYS) for sponsoring and supporting this Family Practice Skills Course.

It has been 5 years since we last organised the Family Practice Skills Course on Function and Disability in Primary Care. There have been more schemes introduced by the Government to help families with family members who have disability – besides the Eldersfield, IDAPE, FDWLC schemes covered in the 2007 course. We now have in addition to these the FDW Grant scheme, the SNSS scheme and the CHAS (Disability) scheme.

The requirements to qualify for the application for the Eldersfield, IDAPE and the FDW Grant scheme are three ADLs of maximal assistance required or total assistance required. For the FDWLC, the SNSS scheme, and CHAS (Disability) scheme, the requirement to qualify for application is one ADL of the 6.

The Family Practice Skills Course is also aimed at an update of the understanding and management of disabilities seen in the child and adult. Disability is a restriction or lack of ability to perform an activity, usually a daily task, in a normal manner.

Disability in children can be broadly classified into physical and mental disabilities. Physical disability is often present in children with cerebral palsy or neuromuscular disorders. With mental disability, the children are not able to learn self-help skills and remain dependent on their caregivers for most of the activities of daily living. Mentally disabled children include those with moderate to severe autism. Long term care and rehabilitation remains the most challenging task for all involved in the care of disabled children. (Ong HT, 2012)¹.

Children with developmental disabilities often show a variety of associated impairments that may result in a lifelong need for additional care. Parents want professionals to recognise and offer explicit acknowledgement of the extra care they give their disabled children. (Choo HT, 2012)².

Important impairments to consider with regards to mobility

and dependency are: lower extremity impairment, upper extremity impairment, visual/ hearing impairment, affective disorders. People with 3 impairments have a 60% likelihood of developing disability in the next one year compared with 7% likelihood among persons with no impairments. Diseases that result in disabilities may be categorised into: musculo-skeletal, neurological, psychiatric, visual, ear diseases and cancers. Ambulation is not only affected by impairments limited to lower limbs – like muscle weakness, joints, nerve problems, but also cardiorespiratory status. (Chan, KM, 2012)³.

The goal of optimal rehabilitation is to restore as maximal a functioning as possible under the circumstances/ limitations posed by residual impairments and the environment. Benefits of rehabilitation include fewer complications, better functional outcomes, a better quality of life and lower medical costs. The rehabilitation team led by the rehabilitation physician is multidisciplinary, providing intensive, goal oriented treatment working towards functional independence. Patient and family involvement are intrinsic to rehabilitation programmes. Caregiver training may be needed, as does assessment of equipment needs, e.g. wheelchair. Continuity of care should be ensured. An understanding of the processes and issues involved in coping with disabilities will help equip the medical practitioner to better provide practical and emotional support, as well as possible strategies to patients. (Lim AC, 2012)⁴.

The assessment of disability including activities of daily living is important as a clinical tool. A practical framework of an independent category and four dependent categories corresponding to an increasing level of assistance for each ADL is used in assessment of ability to perform activities of daily living in adults. Clinicians who administer disability testing on a regular basis will have better inter-rater reliability versus those who perform testing only occasionally or rarely. Rehabilitation improves functional outcomes including the performance of ADLs. (Ng YS & Jung, H, 2012)⁵.

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GAINING INSIGHT INTO PRACTICAL ISSUES BY PHYSICIANS

Adj Assist Prof (Dr) Tan Ngiap Chuan

SFP2012; 38(2): 4

From 2012, Singapore Family Physician enters a new phase with the articles indexed in WPRIM (Western Pacific Regional Index Medicus). This allows wider access of the SFP articles to readers in the Asia Pacific region. In this issue, the secretariat has published a step-by-step instruction for reader to use the WPRIM to search for articles published in the first SFP issue in 2012.

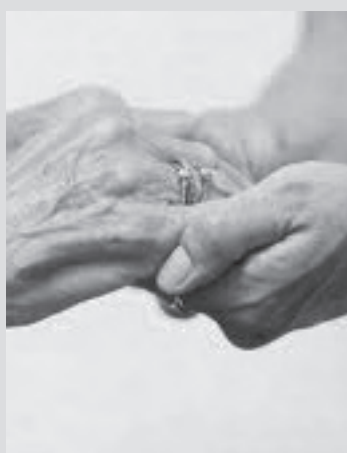
From the third quarter of 2012, SFP will introduce a new category of articles to provide additional educational resource to enrich the knowledge of our primary care physicians. It will be termed “PRISM” or “Patients’ Revelations as Insightful Studies of their Management”. It is frequent for patients to present to primary care physicians unique or unusual scenarios, which either the latter have little knowledge or experience to deal with it or do not have comprehensive or integrative approach in managing the issues, especially in the context of the local socioeconomic, cultural and healthcare system. This category of articles can also cover common presentations or issues, which the physicians have yet to have a consistent approach; this may arise from a paucity of evidence for effective management or complexity due to multiple disciplinary involvement source utilisation of the local healthcare system. The boundary will extend beyond single topic review and will bridge the chasm in areas of family practice that are rarely covered by our specialist colleagues.

TAN NGIAP CHUAN, Honorary Editor, Singapore Family Physician

The article will start with an actual case scenario encountered by the author(s) in their practice, which will include key details on how patient reveals the issue to the physician or clinic staff. The next step is to frame the issue into a clinical question, which will prompt a search for plausible answers or solutions. The authors will search current medical literature for answers and to suggest or recommend possible solutions that can be effectively applied to the specific case scenario presented. The focus is to highlight any gaps of knowledge, delineate the issues and identify the resources that may be available to support the proposed management. Details of this category of articles will be included in the next issue of SFP.

Learning directly from patient’s revelation can therefore be another modality of direct hands-on training for the physicians. Any new knowledge gained should be shared with fellow physicians in the community. If we embrace evidence-based practice, then we should build it on practice-based evidence. PRISM approach provides impetus to expand beyond an insight into single patient’s issues to measurement of the magnitude of such issues in a wider context such as the entire practice or a larger establishment such as a network of primary care clinics.

The editorial team hopes that local physicians will embrace this new approach of medical writing and submit related articles to SFP. It is the aspiration of the editorial team that SFP will become an effective prism to refract the learning bandwidth of our physicians to focus on providing comprehensive, effective and patient-centric primary care and eventually accentuates the practice of family medicine in Singapore.



DISTANCE LEARNING COURSE ON “UPDATE ON FUNCTION & DISABILITY IN PRIMARY CARE”

- Overview of “Function & Disability in Primary Care”
- Unit 1 : Diseases that Result in Disability in Infants and Children – An Update
- Unit 3 : Assessment of Activities of Daily Living in Infants and Children with Developmental Disabilities
- Unit 4 : Diseases that Result in Disability in Adults
- Unit 5 : Rehabilitation and Coping with Disabilities in Adults
- Unit 6 : Assessment of the Six Activities of Daily Living in Adults

OVERVIEW OF “UPDATE ON FUNCTION & DISABILITY IN PRIMARY CARE” FAMILY PRACTICE SKILLS COURSE

A/Prof Goh Lee Gan

SFP2012; 38(2): 6-7

INTRODUCTION

It has been 5 years since we last organised the Family Practice Skills Course on Function and Disability in Primary Care. There have been more schemes introduced by the Government to help families with family members who have disability – besides the Eldershiel, IDAPE, and FDWLC schemes covered in the 2007 course, we now have the FDW Grant Scheme, the SNSS and the CHAS (Disability) scheme. Thanks are due to Centre for Enabled Living (CEL), Ministry of Health (MOH), and Ministry of Community Youth and Sports (MCYS) for sponsoring and supporting this Family Practice Skills Course.

There is also a need to accreditate more family doctors to be assessors of patients in the course of application for one or more of the disability schemes. This accreditation assessment will be conducted on 27 May 2012 at the end of the skills course for new assessors. Existing assessors who are regularly assessing patients will be re-accredited without having to undertake another accreditation assessment.

Updating primary care doctors on the assessment principles, tools, and applications is the objective of this Family Practice Skills Course for all. We would therefore like to encourage all primary care doctors to attend this Family Practice Skills Course.

COURSE OUTLINE AND CME POINTS

This Family Practice Skills Course is made up of the following components. You can choose to participate in one or more parts of it. The CME points that will be awarded are also indicated below.

Components and CME Points

- Distance Learning Course – 6 units (6 Core FM CME points upon attaining a minimum pass grade of 60% in Distance Learning Online MCQ Assessment)
- 2 Seminars (2 Core FM CME points per seminar)
- 2 Workshops (1 Core FM CME point per workshop)
- 10 Readings – read 5 out of 10 recommended journals (maximum of 5 CME points for the whole CME year)

GOH LEE GAN, Professorial Fellow, Division of Family Medicine, University Medicine Cluster, National University Health System, Director, Institute of Family Medicine, College of Family Physicians Singapore

Distance Learning Course

- Unit 1 : Diseases that Result in Disability in Infants and Children – An Update
A/Prof Ong Hian Tat, Dr Chong Shang Chee
- Unit 2 : Rehabilitation and Coping with Disabilities in Infants and Children (The reading material for this unit will be given out at the Seminar.)
Dr Winnie Goh Hwee Suat
- Unit 3 : Assessment of Activities of Daily Living in Infants and Children with Developmental Disabilities
Dr Sylvia Choo Henn Tean
- Unit 4 : Diseases that Result in Disability in Adults
Dr Chan Kin Ming
- Unit 5 : Rehabilitation and Coping with Disabilities in Adults
Dr Peter AC Lim
- Unit 6 : Assessment of the Six Activities of Daily Living in Adults
Dr Ng Yee Sien, Dr Heeyoune Jung

COURSE TOPIC DETAILS

Unit 1: Diseases that Result in Disability in Infants and Children – An Update

- Introduction
- Conditions causing physical disability in infants and children
 - o Cerebral palsy
 - o Paediatric Neuromuscular Diseases
 - o Spina bifida (myelomeningocele)
- Conditions with mental disability in infants and children
 - o Mental retardation
 - o Autistic spectrum disorder
- Strategies to prevent or reduce physical and/or mental disabilities in infants and children

Unit 2: Rehabilitation and Coping with Disabilities in Infants and Children

- Define habilitation and rehabilitation
- The child with disability and the family
- Important component for effective early intervention
- Quality of life and coping with disability
- Functional approach to rehabilitation
 - Assessment and intervention role of therapists
 - Assessment and approach to community living
- Conclusion

Unit 3: Assessment of Activities of Daily Living in Infants and Children with Developmental Disabilities

- Introduction
- Independence in ADL in infancy and childhood
- Existing instruments
- Functional assessment
- Types of disability in children and infants
- Illustrations using case studies
- Conclusion

Unit 4: Diseases that Result in Disability in Adults

- Introduction
- Disease, impairment, disability and the environment
- Diseases that cause disability
 - o Musculo-skeletal disorders
 - o Neurological disorders
 - o Psychiatric disorders
 - o Visual impairment
 - o Ear disease
 - o Cancer
- Ambulation is not just a lower limb problem
- Conclusion

Unit 5: Rehabilitation and Coping with Disabilities in Adults

- Introduction and overview
- Rehabilitation
- Coping with disabilities.

Unit 6: Assessment of the Six Activities of Daily Living in Adults

- Introduction
- Overview and framework of disability assessment
- Current disability assessment tools
- Disability assessment: General principles of disability assessment
- Practical administration of disability assessment: Assessment of the six items of basic activities of daily living in detail
- Rehabilitation and activities of daily living
- Experiences, strengths, weaknesses and conclusions
- Conclusion
- Disclaimer.

FACE-TO-FACE SESSIONS

Seminar 1: 26 May 2012, 2.00pm – 3.45pm

Unit 1 : Diseases that Result in Disability in Infants and Children – An Update

Dr Chong Shang Chee

Unit 2 : Rehabilitation and Coping with Disabilities in Infants and Children

Dr Winnie Goh Hwee Suat

Unit 3 : Assessment of Activities of Daily Living in Infants and Children with Developmental Disabilities

Dr Sylvia Choo Henn Tean

Workshop 1: 26 May 2012, 4.00pm – 5.00pm

Case Studies – Infants & Children

Dr Sylvia Choo Henn Tean & Dr Winnie Goh Hwee Suat

Briefing: 26 May 2012, 5.00 pm – 6.00 pm

Overview of disability related schemes

Insurance perspective of disability related schemes

Seminar 2: 27 May 2012, 2.00pm – 4.00pm

Unit 4 : Diseases that Result in Disability in Adults

Dr Chan Kin Ming

Unit 5 : Rehabilitation and Coping with Disabilities in Adults

Dr Peter AC Lim

Unit 6: Assessment of the Six Activities of Daily Living in Adults

Dr Ng Yee Sien

Workshop 2: 27 May 2012, 4.15pm – 5.15pm

Case Studies – Adults

Dr Ng Yee Sien

Assessment for Accreditation: 27 May 2012, 5.30pm – 6.30pm

UNIT NO. 1

DISEASES THAT RESULT IN DISABILITY IN INFANTS AND CHILDREN - AN UPDATE

A/Prof Ong Hian Tat, Dr Chong Shang Chee

ABSTRACT

Disability in children can be broadly classified into physical and mental disabilities, and there are many conditions that result in this. Physical disability is often present in children with cerebral palsy or neuromuscular disorders. With mental disability, the children are not able to learn self-help skills and remain dependent on their caregivers for most of the activities of daily living. An extension of this group would include those with moderate to severe autism. In paediatrics, many conditions result in both forms of disabilities, with greater consequence and burden to their families. Nevertheless, there have been some recent advances in the management of the spasticity in children with cerebral palsy and the beginning of pharmacological treatment for Duchenne muscular dystrophy. Long term care and rehabilitation remains the most challenging task for all involved in the care of disabled children.

Keywords: Disability in infants and children; cerebral palsy; paediatric neuromuscular diseases; spina bifida; mental retardation; autistic spectrum disorders.

SFP2012; 38(2): 8-15

INTRODUCTION

Disability in infants and children can be broadly categorised into physical and mental disabilities, with some neurological conditions having a combination of both.

Some of the common paediatric conditions associated with significant physical disabilities are cerebral palsy, neuromuscular diseases such as muscular dystrophy, and spina bifida. The universal problems faced by the patient and caregivers include ambulation or mobility, as well as activities of daily living. Some of these children also have cognitive dysfunction, making rehabilitation and long term care a much more challenging task. The comprehensive management of children with physical disabilities includes regular physical therapy, use of orthotic appliances (splints), and appropriate ambulatory aids such as rollators or Kaye-walkers, quadsticks and elbow crutches. Inputs from the occupational therapist on the use of appropriate assistive device, such as splints and Lycra body suits, may help towards functional gains in the motor skills.

ONG HIAN TAT, Senior Consultant, Division of Paediatric Neurology, University Children's Medical Institute, National University Health System

CHONG SHANG CHEE, Consultant and Head, Division of Development and Behavioral Paediatrics, University Children's Medical Institute, National University Health System

For children with mental disability, there is significant limitation in intellectual functioning, and adaptive behavior as expressed in conceptual, social, and practical adaptive skills. Mental retardation, as confirmed through standardised tests of intelligence and adaptive behaviour, is thought to be present if a child has an intelligent quotient (IQ) score of 70 or below, with a significant deficit in at least one area of adaptive behavior¹. For most of these infants with global developmental delay and children with mental disability, the early intervention programme in at-risk infants and children (EIPIC), followed by special education using individualised education programmes, serve to maximise their educational potential. For autistic children with problems in social interaction and communication as well as marked restriction of interests and activities, special education is available in special schools and resource centres. There is some evidence for the use of intensive applied behavioural analysis² in the kindergarten and school setting to help ameliorate some of the autistic behaviours, as well as improve adaptive functioning.

CONDITIONS WITH PHYSICAL DISABILITY IN INFANTS AND CHILDREN

The common paediatric conditions associated with significant physical disability can be divided broadly into those that occur as a consequence of early brain injury resulting in cerebral palsy, paediatric neuromuscular diseases which are often progressive such as muscular dystrophy, and developmental abnormalities in the spinal cord as in spina bifida cystica or spinal dysraphism. Besides these, rare neurodegenerative and metabolic disorders can also result in progressive physical and mental disabilities.

CEREBRAL PALSY

Cerebral palsy (CP) or static encephalopathy, is defined as a disorder of posture and movement secondary to a nonprogressive lesion or insult to the developing brain. The "umbrella term" of CP refers to children with a wide range of static cerebral disorders associated with motor impairment³. Most studies report a prevalence rate of about 2 per 1000 children at 7 to 10 years of age, with moderate to severe mental retardation present in 20 to 30% of these children. In addition, there could also be concomitant specific deficits or impairments in vision, hearing or speech. The type of CP is categorised by the pattern of motor involvement depending on which brain structure in the most affected, i.e. spastic (cerebral cortex), dyskinetic (basal ganglia), ataxic (cerebellum), and mixed. In the mixed form, an ataxic or dyskinetic CP coexists with a spastic CP subtype. The subtypes of spastic CP are further classified based on the distribution of cerebral involvement or motor signs, such as hemiplegia, quadriplegia or diplegia.

Although CP is the commonest cause of motor disability in childhood, in many cases the exact aetiology remains difficult to be ascertained accurately. The more common causes for CP are tabulated in Table 1, and these can be divided based on the timing of the cerebral damage or insult, i.e. prenatal, perinatal or postnatal.

Table 1: Common causes of cerebral palsy

Prenatal

Cerebral malformation syndromes

- agenesis of corpus callosum
- pachygyria-agyria
- schizencephaly
- Dandy-Walker malformation (of the cerebellum)

Maternal deficiencies

- chronic maternal abuses (alcohol, drugs)
- intra-uterine infections (TORCH complex)

Intra-uterine / foetal stroke

- inherited thrombophilic tendency
- placental abnormalities
 - a) foetal vasculopathy
 - b) chorioamnionitis
 - c) placental vascular necrosis

Perinatal

Birth asphyxia (hypoxic-ischemic encephalopathy)

- term infants
- pre-term (low birth weight) babies

Periventricular hemorrhagic infarction

Postnatal

Central nervous system infection

- meningitis
- encephalitis

Traumatic head injury

Shaken baby syndrome

Progressive hydrocephalus (non shunted cases with expanding heads)

Strokes

- thrombophilic tendency
 - a) anti-phospholipid antibody
 - b) factor V Leiden mutation

Of importance is the recognition that the risk of CP is strongly associated with the gestational age with preterm infants accounting for 25% of all patients with CP in Sweden⁴. The risk of CP among every preterm children is approximately one in 20 survivors, compared to the risk of less than one per 1000 survivors in children weighing more than 2500g at birth. This is because in preterm babies, the periventricular watershed areas are fragile and particularly vulnerable to ischemia from mild or transient disturbance in blood pressure that often escapes detection, even by careful monitoring. In preterm babies who develop CP, about two thirds are characterised by the spastic diplegic or ataxic-diplegia type, following periventricular leukomalacia or periventricular haemorrhagic infarction.

The role of infection and/or inflammation in the aetiology of preterm birth has gained prominence in recent years. Preterm

infants had higher rates of exposure to ascending intra-uterine infections. This impression is supported by the frequent findings of positive cultures for infection in preterm CP, as compared to only rare associations with cord blood metabolic acidosis⁵. Studies measuring the inflammatory cytokines in the amniotic fluid showed that these were raised in foetuses that were born preterm⁶. When compared to matched controls, children with CP had more variants of single nucleotide polymorphisms in proteins associated with nitric oxide production, thrombosis, hypertension and inflammation⁷. All these data lend credence to the CP hypothesis by Kendall and Pebbles⁸, who put forward a stepwise pathway of sensitisation followed by injury. Thus, mild hypoxia may be damaging if the foetus' compensatory mechanisms have been down regulated or overwhelmed by another inflammatory insult.

Against widely held assumptions, obstetric complications that can interrupt the supply of oxygen in term infants are rare in survivors and this do not account for most cases of CP. Of these complications, only tight nuchal cord⁹ accounted for 6% of spastic quadriplegic CP. In most term infants who had birth asphyxia, there are often additional risk factors such as intrauterine exposure to infection or coagulation disorders¹⁰, suggesting that more than a single risk factor may often be required to result in an adverse outcome. Similar to preterm babies, markers of maternal infection were associated with an estimated nine fold increase risk of spastic CP¹¹. Most of these infants did not have recognised infections in the newborn period. However, exposure to intra-uterine infection was associated with meconium aspiration syndrome, low APGAR scores and the need for resuscitation, i.e. features that are often mistaken for asphyxia during birth.

Perinatally acquired stroke occurs one in 4,000 pregnancies. This contributes towards a portion of hemiplegic CP and some spastic quadriplegic CP. Almost two-thirds of infants with porencephaly or ischemic stroke had at least one prothrombotic abnormality in their blood¹². Preterm infants who were homozygous or heterozygous for mutation of the enzyme methylene-tetrahydrofolate reductase had a significantly increased risk of developing diplegia¹³. Amongst the many prothrombotic disorders, the presence of anti-cardiolipin antibody was the most frequent prothrombotic factor identified in a group of infants with cerebral thromboembolism¹⁴. Besides anti-phospholipid antibodies, cerebral thromboembolism was reported to be associated with the factor V Leiden mutation¹⁵, the most common genetic thrombophilia. The thrombophilic tendency is often one of the contributory factors to other risk factors such as nulliparity, subfertility, pre-eclampsia, emergency Caesarean section, vacuum delivery, prolonged rupture of membranes and cord abnormalities, with 60% of patients having three or more of these risk factors¹⁶. Abnormalities of the placenta and its vasculature may predispose to thromboses that may then embolise into the foetal circulation, and reach the cerebral circulation via the patent foramen ovale. When placentas were examined in children with CP, the most common

histopathological lesion identified were thrombotic lesions. In some patients, these placental abnormalities were also associated with presence of anti-phospholipid antibodies¹⁷ and the factor V Leiden mutation¹⁸.

For children with CP, the musculoskeletal system is the key area for regular assessment and management. Spasticity is often the major neurological abnormality resulting in loss of motor control, abnormal tone and posture, as well as some degree of weakness. If not managed early, the spasticity can lead to muscle contractures, hip subluxation and scoliosis. Besides orthopaedic surgery which is often indicated when the child is older, the treatment modalities for spasticity in CP includes oral anti-spasticity medication such as baclofen and diazepam, intramuscular botulinum toxin (BTX) type A injections to the spastic set of muscles, intrathecal baclofen pump infusion and selective dorsal (posterior) rhizotomy. There is good evidence from double-blind, randomised placebo-controlled trials demonstrating efficacy of BTX in the management of spastic gait^{19,20} disorders in children with CP, as well as improving the function of the upper extremity of children with hemiplegia CP²¹. The beneficial effects of the BTX injection of usually evident by 2 weeks, and continues to last for 3 to 6 months post-injection. This treatment provides a “window of opportunity” for intensive physical therapy to take place, which often involves stretching of the stiff agonist muscles and strengthening of the weaker antagonist muscles, with the aim of improving functional outcomes. In recent years, the rehabilitation market has seen many new technologically improved and better designed orthotic braces, including those for paediatric use. These new appliances additions include carbon-composite ankle-foot-orthosis, offering stability in addition to assisting the dynamic gait movements, and pre-fabricated supra-malleolar orthosis that provides flexible support to correct abnormal forefoot pronation or supination.

Children with CP are at risk of hip displacement, especially those who are unable to achieve ambulation, e.g. spastic quadriplegics. This is due to progressive hip adductions and flexion, leading to hip subluxation or dislocation and femoral head deformities. As physical examination alone is not reliable in all cases, an anteroposterior radiograph of the hips²² is essential for diagnosis and follow-up measurement of the hip migration percentage. Regular hip surveillance is suggested for children with CP^{23,24}.

In the primary care setting, doctors in family practice need to be aware of the other common complications that can afflict children with CP²⁵. Poor growth and malnutrition is commonly present. This could be due to decreased oral motor skills resulting in prolonged feeding times. There could be swallowing dysfunction resulting in frequent aspiration during feeding. Moreover, there can be unrecognised pain during feeding due to dental caries, gastro-oesophageal reflux disease and often chronic constipation.

PAEDIATRIC NEUROMUSCULAR DISEASES

Physical disability in a child may result following an acute

illness affecting the lower motor neuron, an example of which is Guillain-Barré syndrome (post-infectious or post-inflammatory ascending polyradiculopathy). Another example would be neuromuscular weakness resulting from a spinal lesion, which can present acutely following traumatic spinal injury or infectious transverse myelitis, or present subacutely following an expanding spinal tumour or metastasis.

Most of the children with neuromuscular disorders present with inability to walk since birth or with progressive muscle weakness that results ultimately in inability to walk. The first group includes the more severe forms of spinal muscular atrophy (SMA). In infants with type I SMA or Werdnig-Hoffman disease, the hypotonia is so marked that the infant will not be able to sit up at all before demise in infancy or early childhood. In children with the intermediate form of SMA, i.e. type II SMA, they are able to sit but not walk. Thus, they benefit immensely from the use of motorised wheelchair. With progression of the disease, respiratory support is then needed to prolong their lifespan. SMA is a disease showing autosomal recessive inheritance with an incidence of 1 per 6,000 - 8,000 live births²⁶. The genes that are thought to be involved in SMA include the survival motor neuron (SMN) gene and the neuronal apoptosis inhibitory protein (NAIP) gene, both of which were mapped to chromosome 5q11.2-13.3. The NAIP gene is thought to play a role in modifying the disease severity²⁷ and provides an explanation for the different clinical phenotypes.

The most common progressive neuromuscular disorder is Duchenne muscular dystrophy (DMD), which affects 1 per 3,500 male births. It is caused by mutations in the dystrophin gene²⁸. Dystrophin is a very important protein found in skeletal muscles and its absence renders the sarcolemma fragile, making the muscle fibres susceptible to excessive degeneration with use. In this condition, the boys will be able to achieve independent ambulation although there may be a mild delay in their milestones for walking. The clue to the condition lies in the difficulty for them to climb up steps and later, difficulty getting up from a seated position without the need to push up with their upper limbs. The diagnosis is supported by the presence of markedly elevated serum creatine kinase levels, often reaching 10,000 U/L. With a typical clinical picture and the raised serum creatine kinase, up to 72% of the patients can have their diagnosis confirmed using blood test for the common genetic mutations (deletions or duplications) resulting in DMD²⁹. In the remaining patients, a muscle biopsy is required to confirm the diagnosis when there is absence (or less than 10%) of dystrophin in the muscle fibres. There is recent evidence from randomised controlled trials that corticosteroid therapy, using oral prednisolone 0.75mg/kg/day, for DMD improves muscle strength and function in the short term with benefit lasting 6 months to 2 years³⁰. In addition, there is also some evidence to suggest that deflazacort 0.9mg/kg/day, which is a steroid with lesser side effects such as weight gain, may help preserve the left ventricular³¹ and pulmonary³² function in DMD. The age for initiating corticosteroids is still debatable, but most experts

suggest starting when the gait difficulty develops between the ages of 2 and 5 years²⁹. Thus, there is need for early definitive diagnosis so that treatment can be instituted early to prolong the duration of the child remaining ambulant independently^{33,34}. When no longer ambulant, a motorised wheelchair will allow them to carry on with most of the activities of daily living, in particular, continuing on in school and tertiary education. These patients are encouraged to use the incentive spirometry to maintain their respiratory efforts for as long as possible. A well-fitted wheelchair will slow down the onset of scoliosis, which will further adversely affect their respiratory function. Becker muscular dystrophy, the milder allelic variant, is less common at 1 in 18,500 live births, and tends to have a later onset and a less severe course.

Besides X-linked muscular dystrophy, the limb girdle muscular dystrophies (LGMD) are a group of diseases with progressive, symmetric, proximal muscle weakness with variable onset of presentation, from early childhood to the second decade of life³⁵. The current classification is based on the mode of inheritance and the order in which they are discovered. Type I LGMD have autosomal dominant inheritance, whereas type II LGMD have autosomal recessive inheritance. These patients share many clinical similarities, together with increased myopathic changes on electromyography and signs of muscle fibre degeneration and regeneration on the muscle biopsy. The abnormal gene products had been identified in many of the LGMD. These include proteins assisting the dystrophin in anchoring the muscle cytoskeleton to the extracellular matrix, e.g. proteins making up the sarcoglycan complex. Some of the proteins are instead involved in sarcolemmal signal transduction, e.g. calpain-3 and dysferlin.

Next are the congenital muscular dystrophies (CMD), which is a heterogeneous group of neuromuscular diseases that present in infancy. The typical features are early, usually infantile, hypotonia and motor delay. Creatine kinase may be normal or raised and the muscle biopsies show typical dystrophic changes. The CMD are classified based on the presence or absence of merosin, a protein in the basal lamina of skeletal muscle fibres that links the dystrophin-associated proteins to the extra-cellular matrix. Thus, the merosin-negative CMD are more severe than the merosin-positive CMD³⁶. The merosin-deficient CMD are characterised by more severe hypotonia and contractures. They are accompanied by variable degrees of central (cerebral) hypomyelination³⁷ seen on neuroimaging, and sometimes slowing of nerve conduction velocity³⁸ that indicate a peripheral neuropathy as well. A third group of CMD shows frank structural brain abnormalities, such as neuronal migration defects³⁹, which are not just the hypomyelination described above. This group includes Fukuyama CMD, muscle-eye-brain disease (Santovuori syndrome) and Walker-Warburg syndrome.

Lastly is the group of congenital (structural) myopathies that presents at birth or in infancy with hypotonia, muscle weakness and motor delay. The classification is based on the electron microscopy findings of the muscle fibres. The more common types include nemaline myopathy, central core disease,

myotubular (centronuclear) myopathy, congenital fibre type disproportion and mitochondrial myopathy. Most of these are fairly mild and are often non-progressive or only very slowly progressive (as opposed to the muscular dystrophies). These can be inherited in an autosomal dominant or recessive fashion, with sex-linked form of myotubular myopathy reported as well. Mitochondrial myopathy can present with muscle weakness or often muscle cramp/pain after exercise, and may be associated with lactic acidosis. Other high energy utilisation organ, such as the brain, kidneys and liver, may also be affected. The difference in phenotypic expression and severity is due to the number and distribution of the defective mitochondrial genes in the different organ system in different individuals.

SPINA BIFIDA (MYELOMENINGOCELE)

Spina bifida (myelomeningocele) results from failure of fusion of the caudal neural tube by the 28th day post-conception. The cause for this disorder is heterogeneous and includes chromosomal abnormalities, single gene disorders and teratogenic exposures⁴⁰. Nevertheless, the cause is not known in most cases and the affected individuals do not have an underlying malformation syndrome. However, the risk of spina bifida or anencephaly, or both, in siblings of affected individuals ranges from 3% to 8%, and is consistently higher than that of the general population⁴¹. This underlines the importance of the findings from the Medical Research Council Vitamin Study Research Group, which showed from a multi-centre randomised control trial that maternal peri-conceptional folic acid supplementation provided a 72% protective effect (relative risk ratio 0.28) when compared to controls⁴². Similar results were also obtained from case-controls studies and community interventions. These showed that the lack of folic acid supplementation prior to conception increases the risk of having an affected child by two to eight-fold⁴³. Based on these studies, the recommended folic acid intakes are 4 mg/day for those women at high risk (a previous pregnancy with neural tube defect) and at least 0.4 mg/day for all other women who are capable of becoming pregnant⁴⁴. Besides folic acid, there is also evidence to support a moderate association between low maternal vitamin B12 concentrations and higher risk of neural tube defects (relative risk of 3)⁴⁵.

The severity of the physical disability depends to a large extent on the neurosegmental (functional) level of the spinal lesion. This usually corresponds to the anatomical level of the bony spinal defect as determined by the neuroimaging studies. The neurological deficits result in weakness or paralysis of the lower limb muscles, sensory loss, bladder and bowel dysfunction, and orthopaedic deformities such as clubfoot, hip dislocation, and kyphoscoliosis. Most children with lower lumbar involvement are able to achieve independent walking with the use of ankle brace. With a high lumbar lesion, the children can often walk using elbow crutches with orthotic appliance for the lower limbs. If it is a thoracic level lesion, it becomes increasingly difficult for

the child to ambulate even with aids, and the wheelchair maybe the only realistic option. Besides the physical disability and other complications, individuals with spina bifida are also at risk for central nervous system malformations such as hydrocephalus and Chiari II malformations. The need for shunting increases with the level of the lesion, i.e. most with thoracic lesion required a shunt, whereas less than 70% with a sacral lesion required a shunt⁴⁶. Although most have normal intelligence, language difficulties are more common in children with spina bifida⁴⁷ and this may affect their ability to be independent and economically productive in future.

CONDITIONS WITH MENTAL DISABILITY IN INFANTS AND CHILDREN

Mental Retardation

Most of the children who are confirmed subsequently to have mental retardation using standardised tests of intelligence and adaptive behaviour, already presented with global developmental delay in infancy and early childhood. The areas affected are predominantly in the domains of speech/language, cognition, personal/social skills (including play) and activities of daily living. Mental retardation affects approximately 1% of school-aged children but the diagnosis for the cause of the mental retardation is established in only 30 to 50% of the cases⁴⁸. This is despite a detailed clinical history assessing the pregnancy, perinatal history, family history and social history, as well as a careful examination looking for signs of dysmorphic features and congenital anomalies.

Mental disability could be caused by any condition that impairs the development of the brain before birth, during birth or in the childhood years. The conditions resulting in mental retardation range from congenital dysmorphic syndromes to poverty, malnutrition and maternal education (Table 2). The adverse effect of poor nutrition in early life on cognition is evident with protein-energy malnutrition, iron deficiency in infancy, iodine and vitamin B12 deficiency in childhood. There is a strong inverse relationship between maternal education and prevalence of mental retardation in children without other neurologic conditions⁴⁹. Based on the more common causes listed, some specialised laboratory investigations are required to help ascertain the aetiology. These include cytogenetic analysis for chromosomal abnormalities especially when there are dysmorphic features or family history of mental retardation. After Down syndrome, the next most common genetic cause for mental retardation in boys is fragile X syndrome. Screening for metabolic disorders will provide a higher yield in the presence of parental consanguinity, multiple organ involvement and developmental regression. Magnetic resonance imaging of the brain is more likely to yield a positive result when there are asymmetric neurological findings or abnormal head size.

Table 2: Common causes of mental retardation

Prenatal
Genetic syndromes - Down syndrome - Fragile X syndrome - Prader-Willi syndrome and Angelman syndrome
Inborn errors of metabolism - Phenylketonuria - Organic aciduria (maple syrup urine disease)
Cerebral malformation syndromes (see Table 1)
Maternal deficiencies - Foetal alcohol syndrome - Drug abuse (cocaine) - Intra-uterine infections (ToRCH complex)
Perinatal
Birth asphyxia
Hypoxic state in premature delivery
Postnatal
Central nervous system infection - Meningitis - Encephalitis
Traumatic head injury
Progressive hydrocephalus (non shunted cases with expanding heads)
Environmental toxins - Lead - Mercury
Malnutrition - Protein-energy malnutrition - Mineral and vitamin deficiencies
Poverty and social deprivation
Maternal education

Establishing a diagnosis for the mental retardation is helpful for prognostication and genetic counselling for future pregnancies. For some neurometabolic diseases, specific therapeutic interventions may be possible e.g. dietary treatment for phenylketonuria. Even if no diagnosis is ascertained immediately, it may become apparent with time, in particular with the dysmorphic syndromes. Based on the clinical progress, further specialised tests can be performed or repeated when the need arises.

Autistic Spectrum Disorder

Autistic spectrum disorder (ASD) refers to a disorder of the nervous system that affects the way the brain develops and functions, with onset before 3 years of age. The disorder is characterised by problems with verbal and non-verbal (e.g. gestures and facial expressions) communications, social interactions, usually limited interests and activities, and obsession with routine and order. Often there are some classic repetitive behaviour such as opening/closing doors, flipping light switches, water play and paper shredding. There may also be some motor stereotypes such as hand flapping, body rocking, finger-flicking and self-spinning. Although quite simply defined, the presentation can be extremely variable. Severe cases of autism

with marked impairments in language, poor eye contact and poor engagement with caregivers may be brought to medical attention earlier, while high-functioning, verbal children may demonstrate difficulties only in school-age when social deficits emerge. This clinical nature, together with the lack of well-defined diagnostic tool or a definitive biologic marker or test, contributes to the delay in the diagnosis for many⁵⁰. Although not part of the diagnostic criteria, abnormal responses to various sensory inputs, including auditory, visual, and tactile stimuli, are often also seen in the affected children⁵¹.

In ASD, the children do not always exhibit the same symptoms, and the symptoms also depend on the severity of the disorder. In addition, there are differential diagnoses for autistic behaviours that need to be considered before ascertaining the diagnosis for ASD. The more common amongst these are severe or profound mental retardation and psychiatric conditions such as childhood schizophrenia, bipolar disorders, severe neglect or abuse. The more common neurological disorders with autistic features include fragile X⁵², and tuberous sclerosis⁵³ especially when there is associated malignant epileptic encephalopathy such as West syndrome and Lennox-Gastaut syndrome. Other genetic conditions with significant autistic features include Rett syndrome (mutation in MeCP2 gene) and Angelman syndrome (duplication of chromosome 15q). Generally, it is easy to exclude neurodegenerative disorders with cognitive deterioration and autistic features from ASD because of the absence of the expected ASD clinical feature before the onset of the decline. However, there were some reports indicating that up to a third of children with ASD were noted to have unexplained regression of language and social skills, usually between the age of 18 and 24 months⁵⁴. Thus, specific testing to exclude inborn errors of metabolism may be required in the presence of clinical indications.

Primary care physicians perform an integral role in the surveillance and screening of children for autism spectrum disorder. Surveillance includes identifying high-risk children who have siblings afflicted by autism, or children in whom caregivers, parents or the physician himself is concerned about features of autism. Specific screening tools like the M-CHAT (Modified Checklist for Autism in Toddlers) are recommended as next steps for these high-risk children, and also currently encouraged as routine at 18 or 24-30 month health visits^{55,56}. Currently, tools like the Autism Diagnostic Observation Schedule (ADOS) and Autism Diagnostic Interview- Revised (ADIR) have been well-validated as standardised diagnostic tools for autism spectrum disorder⁵⁵.

Early screening and diagnosis allows for early intervention, which has been shown in various longitudinal outcome studies to better cognitive and behavioural outcomes⁵⁷. Although there is no medical treatment for ASD, many of the co-morbid symptoms such as obsessive compulsive behaviour, aggression and hyperactivity, and sleep disturbance can be managed and treated accordingly. Clearly, there is now a greater need for early diagnosis of ASD as better cognitive and behavioural outcome is possible with early intervention programmes, and in particular, the use of intensive applied behavioural treatment starting as early as 4

years of age 2. Parental education and support together with the early intervention strategies in the community can help children with ASD maximise their developmental potential.

STRATEGIES TO PREVENT OR REDUCE PHYSICAL AND/OR MENTAL DISABILITIES IN INFANTS AND CHILDREN

A. Before Pregnancy

- 1) Genetic counselling
 - (a) history of an affected child with suspected genetic/ chromosomal disorder
 - (b) history of two or more miscarriages or a baby who died in infancy
 - (c) mother is 35 years of age or more
 - (d) consanguineous parents
- 2) Avoid alcohol, illegal drugs, and smoking
- 3) Proper balanced diet and vitamin supplementation, including folic acid
- 4) Review the medication(s) that woman is on
- 5) Updating immunisations (e.g. rubella if not previously done)

B. During Pregnancy

- 1) Early prenatal care and follow-up
- 2) Adequate rest and sleep
- 3) Nutrition meals

C. Prematurity and Low Birth Weight Baby

D. Newborn

- 1) Screening
 - (a) congenital hypothyroidism
 - (b) inborn errors of metabolism

E. Infancy

- 1) Vaccination against
 - (a) measles and rubella
 - (b) hemophilus influenza
 - (c) invasive pneumococcal disease

F. Childhood

- 1) Preventive measures against traumatic brain injury
 - (a) safety seat (child car seat) and safety belt when travelling in a car
 - (b) use of bicycle helmets
 - (c) water safety against drowning or near-drowning
 - (d) home safety to prevent accidental falls
- 2) Reduce exposure to environmental toxins that result in brain damage
 - (a) lead
 - (b) mercury
- 3) Reduce poverty and social deprivation
- 4) Emphasise the need for a balanced diet

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LEARNING POINTS

- **Disability in children can be broadly classified into physical and mental disabilities.**
 - **Physical disability is often present in children with cerebral palsy or neuromuscular disorders. With mental disability, the children are not able to learn self-help skills and remain dependent on their caregivers for most of the activities of daily living.**
 - **Mentally disabled children include those with moderate to severe autism.**
 - **In paediatrics, many conditions result in both physical and mental disabilities, with greater consequence and burden to their families.**
 - **Long term care and rehabilitation remains the most challenging task for all involved in the care of disabled children.**
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UNIT NO. 3

ASSESSMENT OF ACTIVITIES OF DAILY LIVING IN INFANTS AND CHILDREN WITH DEVELOPMENTAL DISABILITIES

Dr Sylvia Choo Henn Tean

ABSTRACT

Children with developmental disabilities may need extra care due to delayed development of self-care skills and/or a need for special care. Delayed self-care skills mean that care needs that are expected to diminish in typically developing children, persist.

Whether a child is independent in an aspect of self-care would be dependent on his chronological and developmental age, developmental disability and the associated impairments, as well as cultural and other environmental factors, such as the child's gender, the presence of a domestic helper, early attendance at preschool. Family circumstances should also be taken into consideration.

The functional assessment of ADL in infants and children with developmental disabilities has been distilled into the domains of Washing/Bathing, Dressing, Feeding, Toileting, Transferring and Mobility. They reflect the activities that occur in the typical day in the life of a child. Common developmental disabilities and possible effects on acquisition of independent ADL are discussed.

Keywords: Assessment; activities of daily living (ADL); self-care; developmental disability; children.

SFP2012; 38(2): 16-20

INTRODUCTION

All children have a right to care by a parent or trusted adult. As infants, this care extends to every aspect of the child's life: bodily functions, and physical, mental and emotional development. As the child grows, the care required changes and generally diminishes. Children with developmental disabilities require the same care and parenting as other children, with the addition of extra care due to impairments or chronic ill health. The extra care required may arise from delayed development of self-care skills and/or a need for special care. Delayed self-care skills mean that care needs - which are expected to diminish in typically developing children - persist. Special care needs 'go beyond the bounds of ordinary parenting', for instance involving ventilators or feeding tubes.

Developmental disabilities are a group of chronic disorders of early onset estimated to affect 5 to 10% of children¹. In more technical terms, these children often have a variety of

associated impairments that may sometimes lead to limitations in the capacities of the child. According to the International Classification of Functioning, Disability and Health (ICF), capacities describe the individual's ability to execute a task or an action, and are defined as the highest probable level of functioning that a person may reach in a given domain at a given moment in a 'standardised or assumed' environment. Limitations in the capacities of the child will lead to the need for additional care. This additional care has been defined as 'dependency on medication or special diet, medical technology, assistive devices, personal assistance, need for medical care or related services or educational services over and above the usual for the child's age, or for special ongoing treatments, interventions or accommodations at home or in school'².

In a study of the families of 40000 disabled children in the UK, the majority of the children required extra assistance or supervision with multiple areas of daily life. The study also indicated variety in extra care tasks undertaken (physical help, supervision, guidance) and causal factors (physical limitation, cognitive difficulties, behavioural problems). In particular, the findings indicated that parents want professionals to recognise and offer explicit acknowledgement of the extra care they give their disabled children³.

Certainly, taking into considering the child's family circumstances are also important. Families often have more than one child, and sometimes, more than one disabled child. Single parents may often have to care for their disabled children alone. Besides recognising and acknowledging the care that parents provide for their children with disabilities, it behoves us to offer family-centred care and assist with decision-making in a family-centric and not merely child- or patient-centric way.

INDEPENDENCE IN ADL IN INFANCY AND CHILDHOOD

Whether a child is independent in an aspect of ADL would be dependent on his chronological and developmental age, as well as cultural and other environmental factors. In typically developing children, there is generally an age range at which a certain ADL is achieved, but again, external cultural and other environmental factors need to be taken into consideration. In a study on normal Hong Kong Chinese children, some gender and culturally specific aspects (e.g. the presence of a maid at home, early attendance at preschool) were found to impact on the performance of functional skills. In general, girls mastered self-care and communication competencies before boys⁴.

Crucial to measuring functional limitations is defining essential daily tasks. These may include self-care activities of

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feeding (using a cup, spoon, and fork), grooming (washing face and hands, brushing teeth, combing hair), dressing upper body (shirts/blouses), dressing lower body (underwear, pants, shoes and socks), adjusting clothes, maintaining bladder and bowel continence, and wiping after toileting. Motor activities include changing positions from chairs, getting on and off the toilet or potty, getting in and out of the bathtub or shower, walking indoors and outdoors, and ascending and descending stairs.

The list of these activities reflects that during a typical day a child must complete a meal independently using appropriate utensils or be assisted in feeding. The child, during a typical day, will wash hands and face, brush teeth, comb hair, or be assisted in these areas. A child, on a typical day, will dress and maintain continence or require assistance or diapers. A child will generally ambulate indoors and outdoors, get in and out of chairs, on and off toilets, in and out of showers, negotiate stairs, or be assisted with these tasks.

EXISTING INSTRUMENTS

Currently, paediatric health professionals have several choices for adaptive-functional instruments. These include the WeeFIM (Functional Independence Measure), the Pediatric Evaluation of Disability Inventory (PEDI), the Battelle Developmental Inventory (BDI), and the Vineland Adaptive Behavior Scales (VABS). The PEDI, BDI and VABS are maximum data sets and involve detailed and extensive queries of self-care, mobility, communication and social items. On average, they require >30 minutes of interview time and complex scoring^{5,6}. The WeeFIM is useful in assessing functional independence in children aged 6 months to 7 years (up to 21 years in people with developmental disabilities), and can be administered by a trained interviewer in approximately 15 minutes⁷. A simple screening questionnaire, the measurement of activities of daily living (M-ADL), has been standardised and recently, validated in Germany. The M-ADL does not require trained interviewers, takes about 5 minutes to administer, and may serve as a tool for quick information on the level of activities according to the International Classification of Functioning, Disability and Health (ICF)^{8,9}.

In the Netherlands, a Capacity Profile (CAP) has been developed to classify and measure additional care needs in children aged 3 to 18 years with permanent, non-progressive neurodevelopmental disabilities. Preliminary evidence suggests that the need for additional care is relatively stable over time for this group of children and that CAP, if validated by prospective studies, may be used to classify the consequences of neurodevelopmental disorders¹⁰.

FUNCTIONAL ASSESSMENT

Washing/Bathing

Typically developing children in Singapore often start bathing

independently from the age of five or six. Children exposed to day care may bathe independently earlier.

Extra care with washing may be needed because of a physical inability to wash or extra care for delicate skin. Frequent vomiting, diarrhoea, or weeping wounds necessitate repeated washing.

Dressing

From about 18 months, toddlers often assist with dressing and undressing, taking off shoes. By the age of three, he is able to pull his pants down and up, but needs help with buttons and other fastenings. Most five-year-olds are able to undress and dress independently.

Extra help when dressing may include practical help because of stiff or floppy limbs, repeated changes due to incontinence or dribbling, or guidance for a visually impaired child.

Feeding

An 18 month old toddler can hold a spoon and get food safely to his mouth, although he may also play with the food. He is able to hold his cup between both hands and drink without much spilling. By the age of two, he is able to feed himself competently with a spoon, but is easily distracted. He is able to lift a cup and drink well without spilling, and replace the cup on the table without difficulty. He is able to ask for food and drink. By the age of four, he is able to eat skillfully with a fork and spoon.

A child who finds chewing and swallowing difficult or requires tube feeding needs extra care at mealtimes, while children with behavioural disorders or insatiable (e.g. in Prader Willi Syndrome), or inappropriate (e.g. Pica) appetites require close supervision.

Toileting

Many toddlers begin to give notice of urgent toilet needs by restlessness and vocalisation. Bowel control may be attained but this is variable. They may indicate wet or soiled pants.

Encopresis is defined as regular soiling of the underwear in children aged four years and older, with no organic disease. The soiling can range from staining the underwear to semiformal or formed stools. Enuresis is defined as a lack of urinary continence beyond the age of four for diurnal enuresis, a lack of urinary continence beyond the age of six for nocturnal enuresis, or the loss of continence after at least three months of dryness.

Young disabled children may need extra care when toileting due to bladder and/or bowel incontinence, stoma care, catheterisation or poor skin. Although most children are toilet trained by the age of three, this process is often prolonged or unsuccessful for disabled children.

Transferring and Mobility

Toddlers from the age of about 18 months are generally able to walk well and run carefully, with rapid improvement of locomotor skills from about two and a half years. Two year

olds enjoy climbing, and will climb forward into an adult's chair, then turn round and sit. By the age of four, they are able to walk or run alone up and down stairs, one foot to a step in adult fashion.

Inaccessible toilet facilities may mean an older physically disabled child continues to require adult assistance, while other disabled children find it hard to manage personal hygiene alone.

Additional Care for children with special needs may also include the following:

- Extra care at night, e.g. turning an immobile child, giving medication or tube feeds
- Supervision for children with special needs when they are awake, as some may have frequent seizures, or lack an awareness of danger
- Behavioural problems ranging from inconsolable and constant crying in younger children to self-harm, destructiveness and violent or attention seeking behavior in older children.

TYPES OF DISABILITY IN CHILDREN AND INFANTS

In the form for application for FDW levy concession for persons with disabilities, the disability types have been divided into six main categories.

Physical

These would include congenital structural malformations as well as neuromuscular disorders, which affect motor function. In general, these disorders present fairly early, e.g. structural malformations such as spina bifida and arthrogryposis multiplex congenital would be picked up in the neonatal period. Other 'physical' disabilities such as cerebral palsy, Duchenne Muscular Dystrophy and other neuromuscular disorders generally present in the first to third year of life.

Intellectual

There is some confusion about the label "Global Developmental Delay" (GDD). This is a subset of developmental disabilities defined as significant delay in two or more of the following developmental domains: gross/fine motor, speech/language, cognition, social/personal, and activities of daily living. GDD describes a clinical presentation that has a heterogeneous aetiologic profile and is associated with age-specific deficits in adaptation and learning skills. Those deficits are evident in comparison with the skills attainment of chronological peers. The term GDD is usually reserved for younger children (i.e. typically less than five years of age), whereas the term mental retardation is usually applied to older children when IQ testing is more valid and reliable. However, a child with the clinical picture of GDD is not necessarily destined to be

mentally retarded. Infants and children may have GDD owing to conditions such as cerebral palsy, certain neuromuscular disorders, and other conditions such as early environmental deprivation, yet when they are old enough to measure cognitive level they do not score in the mentally retarded range¹.

Autism Spectrum Disorder

As this is a 'spectrum disorder', the symptoms, abilities, and characteristics are expressed in many different combinations and in any degree of severity. Hence, children with autism vary widely in their cognitive, language, and social abilities, with a variety of strengths and weaknesses. At one end of the spectrum, we may find a mute child, crouched in a corner of the room, spinning a paper clip over and over again for hours; at the other end of the spectrum is a highly verbal, mathematically and scientifically gifted boy in the Integrated Programme, but with significant difficult social difficulties.

Their major deficit is in interactive social relationships and social communication, both verbal and non-verbal. Many children with ASD also have restricted interests and activities.

Sensory

This category is generally fairly straightforward, and would include children with a single sensory impairment, such as Visual or Hearing Impairment.

Multiple Disabilities

Children with multiple disabilities, such as coexisting cerebral palsy with mental retardation, or children with two sensory impairments, would fall into this category.

ILLUSTRATIONS USING CASE STUDIES

Spina Bifida

V is a 7-year-old Indian girl with T12 spina bifida diagnosed only at delivery. This was surgically repaired on day 1 of life. A ventriculoperitoneal shunt was also inserted for hydrocephalus. She is presently attending primary one at a mainstream primary school, with therapy support from Teach Me services. Her father works shifts as a security guard whilst her mother is a homemaker, and her main caregiver. V has an older brother and a younger sister.

She is able to use a cup, spoon and fork without help; her mother cuts her meat. She independently brushes her hair, brushes her teeth, and washes her face and hands without help. V is able to wash and rinse during bathing; her mother assists in drying. She puts on and removes t-shirts. Her mother helps her in fastening her zippers. V requires a lower extremity orthosis; she is able to perform 75% of the effort of applying it. She is able to put on and take off her shoes and socks. She cannot wipe herself after toileting. Her mother adjusts her clothes after her bowel movements.

V is on Ditropan for bladder spasticity, and uses clean intermittent catheterisation; she successfully passes the catheter half of the time, and has bladder accidents on a daily basis. She uses a bowel catheter, which her mother must administer twice a week. She has no stool accidents at other times.

V's mother helps her transfer onto the toilet. She cannot do a standing pivot or slide transfer. She can transfer in and out of bed when she is not wearing her brace. V requires a wheelchair for outdoor activity. She does most of the transfer from chair to wheelchair. She has a walker for household use and can safely traverse a room using the walker. V cannot crawl and must be lifted up stairs.

V can understand fully ordinary conversation and follow a three-step related command. She expresses basic needs and ideas about everyday situations clearly and fluently without help. V plays board and card games with her friends without adult supervision. She knows all the rules and can instruct other children in how to play. V recently dropped a plate and made sure her one-year-old brother did not crawl into the glass.

Points to note:

- Cognitively high-functioning child, but needing help with many self-care activities.
- Supportive mother who is enabled, in an intact home environment.

Down Syndrome

AR is a four-year-old Malay boy with regular trisomy 21, delivered at term. He has a surgically repaired atrioventricular septal defect and is the fourth child of mature parents, who are very supportive and understand his disability.

Presently, AR is attending an EIPIC programme twice a week. He walked independently at age two, and has a steady gait. However, he is unaware of danger, and often climbs onto tables and chairs, to look out of the window. He is able to address his family members, and uses mainly single words, having difficulty with receptive and expressive language skills. His attention span is short, and he is unable to follow most instructions. His behaviour is often self-directed and he has difficulties with unsupervised play and problem solving. AR needs help with dressing, he is still on diapers throughout the day, and tries to use a spoon to feed himself, but is messy. Bath time is often prolonged and challenging, as AR often refuses to get out of the bath. AR's mother has reported that it is a challenge looking after him, and that she is often exhausted at the end of the day.

Points to note:

- Supportive mother, who is not well enabled to care for her son's special needs
- Behavioural difficulties a challenge to his elderly caregiver

Autistic Spectrum Disorder

A is a 13-year-old Chinese girl with Autistic Spectrum Disorder with moderate intellectual disability, diagnosed when she was 3 years old. Her father works long hours as a taxi driver. Her mother is a homemaker, and is A's main caregiver. She has two other younger neurotypical siblings.

A is attending classes in a special school. She takes the school bus, but needs her mother to wait with her at the bus stop, as she sometimes still steps onto the road without looking to see if cars are coming. She is able to indicate some of her basic needs by gesture or signing, but has no speech. She has learned to wash, dress, and feed herself. She has also learned to cut out shapes with a pair of scissors. However, she has not learned to read, write or speak. At school, she is said to be compliant, and able to follow the school routines and schedules well. Too well, sometimes, as A is upset if there are changes in routine.

A has a flat affect, and when she is at home, often engages in repetitive self-stimulatory behaviour, such as rocking. Her favourite activity was, and still is, watching cartoons on television. She replays the same cartoon videotape over and over again.

When she turned 12, A developed epilepsy. This is fairly well controlled on anticonvulsant medication. However, she also began to have more frequent and severe temper outbursts. She would scream, shout, throw objects and even push her mother. Often, it would take more than an hour for A to calm down. It was often difficult for A's mother to tend to her needs and to those of her siblings, as well as the household chores. A was finally brought to see the child psychiatrist, who prescribed medication that has helped her tantrums. A daily routine and structure were also established for A, with scheduled times for waking up, washing, meals and watching television.

Points to note:

- Although A is a teenager, she requires care that is usually extended to perhaps a four-year-old.

Multiple Disabilities

JX is a five-year-old Chinese boy, delivered prematurely at 24 weeks, birth weight 530g. He has spastic quadriplegic cerebral palsy, with spasticity of all four extremities, microcephaly and cognitive impairment. He is also blind with retinopathy of prematurity, and hearing impaired, on hearing aids.

JX had a stormy perinatal period. He had severe hyaline membrane disease, with recurrent pneumothoraces, needing high frequency ventilation, and hypotension, on dopamine and dobutamine inotropic support. JX subsequently developed necrotising enterocolitis, which was conservatively managed, Stage 3 ROP with plus disease, needing laser photocoagulation, bilateral sensorineural hearing loss. He was finally discharged when he reached a weight of 2 kg, with home oxygen for chronic lung disease. JX was weaned off the oxygen when he was about eight months old. Cranial ultrasound showed bilateral cystic periventricular leucomalacia.

His parents separated a year after JX was discharged from hospital. He had multiple readmissions for exacerbations of his chronic lung disease. Presently, his mother is working part-time as a sales promoter, and his maternal grandmother takes care of him whilst his mother is at work. However, grandma is in her mid-seventies, and also has medical problems of her own. JX’s father does not contribute to or participate in his care.

JX is attending the Programme for Children with Multiple Handicaps at Rainbow Centre. He has minimal self-mobility, and spends most of his waking day sitting up in a wheelchair. He is totally dependent in all activities of daily living, and although he has no speech, he is socially responsive and recognises his caregivers.

Points to note:

- Multiple severe disabilities, long term prognosis quite clear - will require lifelong care for most areas of ADL
- Single parent, with little family or community support

CONCLUSION

Children with developmental disabilities are a heterogeneous group with diverse clinical presentations, abilities and difficulties. It is important to consider each child and family individually. Care should be taken to consider the impact of the child’s impairments on requirements for extra care across all areas of daily life, as well as the individual family circumstances.

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LEARNING POINTS

- **Children with developmental disabilities often show a variety of associated impairments that may result in a lifelong need for additional care.**
- **Parents want professionals to recognise and offer explicit acknowledgement of the extra care they give their disabled children.**

UNIT NO. 4

DISEASES THAT RESULT IN DISABILITY IN ADULTS

Dr Chan Kin Ming

ABSTRACT

The common types of disabilities in adults are those of the locomotor system which affects mobility, those affecting activities of daily living (ADL), hearing and sight. These disabilities may be caused by a variety of diseases. Diseases of musculoskeletal, neurological, eye, ear, and psychiatric origin, as well as cancers, may lead to impairments which when severe lead to disability in mobility as well as in performing essential self-care activities. Important impairments to consider with regards to mobility and dependency are lower and upper extremity impairments, visual/ hearing impairment, affective disorders and poor balance. Ambulation is not only affected by impairments to lower limb but also by compromised cardiopulmonary status.

Keywords: disability, activities of daily living (ADL), impairments, locomotor disabilities, hearing loss, vision loss

SFP2012; 38(2): 21-23

INTRODUCTION

The 4 common types of disabilities found in adults are those affecting the locomotor system, activities of daily living, hearing and sight. Among adults reporting disability, the most common is difficulties in climbing stairs (about 10%) and walking 3 city blocks (10.3%). The number of people reporting disability increases with age. Women tend to have a higher prevalence than men at all ages. Given the size of baby boomers, the number of adults with disabilities is likely to increase dramatically¹.

Older people tend to have more disease and disability than younger adults. They often have many diseases at the same time and most of the diseases are chronic. Disease and disability can greatly limit independence and increase the need for support. How well a person functions is determined by the ability to perform essential self-care activities (usually called activities of daily living), such as eating, dressing, bathing, transferring between bed and chair, and using the toilet. In a community study done in Singapore to assess the functional status of those 60 years and older, 17% were dependent in at least one area of ADL and 10.4% had at least one IADL that they could not perform². How well a person functions is also determined by

the ability to perform additional important activities (usually called instrumental activities of daily living), such as preparing meals, performing housework, taking drugs as instructed, going on errands, managing finances, and using a telephone. While many elderly people have the strength to perform these tasks, they may not have the volition to do so, as seen in many with dementia or depression. Hence, it is not just important to assess their musculo-skeletal and neurological system for ability, but also their mental status for volition.

DISEASE, IMPAIRMENT, DISABILITY AND THE ENVIRONMENT

Disability of a person can be affected by diseases. The WHO conceptual framework proposes a stepwise process by which disease may lead to disability³:

- Disease is an intrinsic pathology or disorder which may or may not be manifested, that is, disease may be clinical or subclinical.
- Disease that becomes clinical may lead to impairment. Impairment is the loss or abnormality of structure or function at organ system level. A disease like diabetes may cause renal and visual impairment. When the impairment becomes more severe, a disability may result.
- Disability is a restriction or lack of ability to perform an activity, usually a daily task, in a normal manner. A single disability may be caused by a number of different impairments, e.g. walking disability may be caused by visual impairment, peripheral nerve impairment (peripheral neuropathy), and joint impairment (arthropathy).

Along the path of disease to impairment and then disability, other factors come into play to influence it, e.g. cognition, education and culture, psychological factors (gender, race and age), physical environment, financial, etc. Someone with DM retinopathy may have a visual impairment, but may not be disabled by it because of a bright environment. In the night or dark room, he may become disabled. Similarly, a person with a stroke may be able to walk in the flat flooring of his own home, but outside, he can be disabled by stairs and the uneven pavement beside the road.

Important impairments to consider with regards to mobility and dependency are: lower extremity impairment, upper extremity impairment, visual/ hearing impairment, affective disorders. Someone with 3 impairments has a 60% likelihood of developing disability in the next one year compared with 7% likelihood among persons with no impairments.

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DISEASES THAT CAUSE DISABILITY

Diseases that result in disability can be categorised into:

Musculo-skeletal disorders – arthritis, fractures, myopathy, contractures, and amputations. Among these, arthritis is the most common cause of disability in adults⁴. It is quite obvious that any disorders in the musculoskeletal system will affect mobility. The lower limbs serve as a prop to keep the body upright. If there is a breach in that prop, like a painful joint, a fractured bone, joints that are bent (contractures); it would be difficult to maintain that posture. Weakness of muscles can result from disuse atrophy or myopathy (from diabetes, steroid induced, hyponatremia, hypokalemia, hypocalcemia, or osteomalacia). While these are common causes and should be first thought of, there are less common conditions which must be considered e.g. polymyalgia rheumatica, giant cell arteritis, which if not treated, can cause serious disabilities including blindness.

Neurological disorders – peripheral neuropathy, stroke, Parkinson's disease and deconditioning.

These causes affect muscle strength, proprioception and balance of the person, as well as reaction of the person to falls. The inability of the person to stretch out their hands (fast enough) to grab a nearby object or to break the fall can lead to higher incidences of fractured hips rather than fractured wrists (Colles fracture). This explains the higher incidence of fractured hips in older persons (> 80 years) compared to fractured wrists in the young old. In deconditioning, while all of us suffer from it as a result of inactivity, the older person seems to be affected by it more quickly. For every 24 hours of bed rest, the person loses 5% of muscle tone and this is translated clinically into weaker muscles. In addition, the longer he lies in bed, his sense of position and posture is also affected, and we often see these patients having a tendency to fall backwards when they get up. Deconditioning not only affects muscle strength and tone, it also causes muscle atrophy and joint contractures, further delaying the recovery process^{5,6}.

Psychiatric disorders – Dementia and Depression.

Dementia is a condition of global degeneration of the brain, affecting first the memory (recent memory), and later the other cognitive domains (language, executive function and visual spatial cognition). Changes in executive function and visual spatial cognition may lead to apraxia – an inability to perform a function even though muscular function is adequate⁷. Moderate or severe dementia may be associated with frequent falls, which in turn lead to the psychological fear of falling, immobility, deconditioning and contractures. They are also more frequently associated with falls related injuries (due to lack of safety awareness).

Depression is often a comorbidity of any chronic disease⁸. In any of these, it tends to worsen the condition. In chronic painful conditions, it makes the pain even more unbearable, adding sleep disturbance, poor appetite, social withdrawal and apathy to the other chronic disease symptoms. In short, the disability of the underlying chronic disease is made worse than what it actually is. For example, a stroke patient cannot walk because he does not want to try, and not because he is not able to (from the neuromuscular point of view). This should be recognised and treated early.

Both dementia and depression can lead to loss of volition for the person to do anything. They may be just contented to sit and do nothing. Even when advised to exercise, they do not see the need to do so, sometimes even insisting that they are well. Such loss of drive accelerates deconditioning.

Visual impairment

Visual impairment, from cataract, retinopathy (e.g. diabetic retinopathy), glaucoma or macular degeneration, is a common cause of ADL disabilities⁹. The disability worsens when the environment is dark or cluttered, obstructing the path of the person. Having bright lights and clutter free will lessen the disability of the person. Treating the retinopathy, maculopathy, glaucoma or cataract surgery will help to improve the condition.

Ear disease

Ear disease causing giddiness and vertigo can also cause imbalance, falls and immobility. Common causes of hearing impairment include impacted ear wax, perforated tympanic membrane, Meniere's disease or just age-related hearing loss or presbycusis⁹.

Cancer

Cancer, a common disease in older persons, causes disability through the site of primary tumour (e.g. brain, bone, and lung), secondary deposits (spinal metastasis, lung or brain secondary), complications of the tumour (bleeding causing anemia, general cachexia, pulmonary effusion, pain, non metastatic manifestations, e.g. myopathy) or complications of treatment.

AMBULATION IS NOT JUST A LOWER LIMB PROBLEM

Ambulation is not only affected by impairments limited to lower limbs – like muscle weakness, joints, and nerve problems – but also cardiorespiratory status. Walking on level ground, BK amputee uses 9-20% more energy than someone without; while AK amputee uses 45-70% more energy than the non-amputee. Those with bilateral AK amputations use 300% more energy¹⁰. So by varying walking rate, the person can compensate for the

impairment. Hence, someone with only heart problem has twice the risk of developing difficulty in walking; with arthritis, a four-fold increase, but with both, 14-fold increase.

Cardiovascular conditions include heart failure (severe enough, may become 'cardiac cripple'), and severe coronary arterial disease (unstable angina or angina with mild activity), and cor pulmonale (right heart failure secondary to a chronic lung condition). Respiratory conditions like chronic obstructive airway disease, emphysema or cancer of the lungs will also limit the functional ability of such patients through effort related breathlessness.

CONCLUSION

One should not just look at the upper and lower limbs integrity in assessing functional ability or disability, but also beyond that, to the mental and cardiovascular and respiratory status of the person.

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LEARNING POINTS

- **Disability is a restriction or lack of ability to perform an activity, usually a daily task, in a normal manner. A single disability may be caused by a number of different impairments.**
- **Important impairments to consider with regards to mobility and dependency are: lower extremity impairment, upper extremity impairment, visual/ hearing impairment, affective disorders.**
- **People with 3 impairments have a 60% likelihood of developing disability in the next one year compared with 7% likelihood among persons with no impairments.**
- **Diseases that result in disabilities may be categorised into: musculo-skeletal, neurological, psychiatric, visual, ear diseases and cancers.**
- **Ambulation is not only affected by impairments limited to lower limbs – like muscle weakness, joints, nerve problems, but also cardiorespiratory status.**

ABSTRACT

The ultimate goal of Rehabilitation is for optimal functioning and independence of the patient. This includes the physical, psychological, social, educational, vocational, and recreational abilities and participation. It is holistic in nature and addresses restoration where possible or compensation where necessary. Rehabilitation Medicine is the medical field specialising in care of patients with disabling disease or injury.

The person with disabilities has to cope with many changes including physical, psychological and cognitive. They go through an adjustment or crisis coping process, and there are various strategies and philosophies that help with healthy coping.

An understanding of the options and processes involved in rehabilitation, as well as how patients cope with adversity, is important to the family practitioner as the aging of Singapore will result in increasing numbers of patients presenting with disabilities needing more than simply medicines.

Keywords: rehabilitation team, inpatient rehabilitation, changes in disability, coping skills model, adjustment dynamics, healthy coping

SFP2012; 38(2): 24-31

INTRODUCTION AND OVERVIEW

The US Census Bureau, with statistics from the 2008 American Community Survey reported that 36.1 million people or 12.1% of the civilian non-institutionalised population aged five years and older reported at least one of six types of disability. Approximately 3.5% experienced difficulty hearing (deaf or serious difficulty hearing), 3% experienced difficulty seeing (blind or difficulty even when wearing glasses), 4.8% have cognitive difficulty (concentrating, remembering or making decisions), 6.9% had ambulatory difficulty (walking or climbing stairs), 2.6% had a self-care difficulty (dressing or bathing), and 5.5% had independent living difficulty (doing errands alone or shopping)¹.

The World Report on Disability 2011, a joint publication by the World Health Organisation and the World Bank, used the International Classification of Functioning, Disability and

Health (ICF) to categorise problems with functioning in three interconnected areas namely Impairment, Activity Limitation, and Participation Restriction. It estimated that between 15.6% (World Health Survey) to 19.4% (Global Burden of Disease) aged 15 and older lived with disability, with between 2.2% to 3.8% being “very significant” or “severe” such as tetraplegia, severe depression, or blindness. When children are included, about 15% of the world’s population live with a disability².

The family practitioner is often at the forefront of contact with these patients, and having a good understanding of the rehabilitation process, options available, as well as how people cope with a disability is essential.

Healthcare may be divided into three categories: Preventive, Curative, and Rehabilitative. Although society’s emphasis on these three areas may vary at different times, e.g. during epidemic or war, the third category is unfortunately often last in priority and consideration. Nevertheless, it is a reality that disability can strike anyone at anytime and it has been said, “becoming disabled is like belonging to a club that nobody wants to join, but one that anyone could join” Another thoughtful viewpoint is that being able-bodied is only transitory, as one is “disabled” in the initial stages of life, and having a disability is almost inevitable as one gets old.

The fact that Singapore is one of the fastest aging countries in the world has been well-publicised. As per the 1999 Report on the Inter-Ministerial Committee on the Ageing Population, 19% of the population, or about one in every five, will be 65 years and older by 2030³. Singapore also has a high life expectancy of 80 years for males and 84 for females⁴. These are important considerations as there is a strong correlation between age and disability. Only 5% of those aged 18 years and younger have some activity limitation. This goes up to 40% in those 65-69 years, and is almost 60% in those 85 years and older. Depending on the age, the activity involved may be ability to attend school, play, work, keeping house, and being able to take care of oneself⁵.

Plummeting birthrates in Singapore with a Resident Total Fertility Rate per female of 1.15 in 2010⁴, greater female participation in the labor force, smaller families to share the caregiving burden, and modern day individualistic expectations, have resulted in the tradition of families available to take care of their infirm and disabled difficult, if not impossible. The patient’s expectations regarding independence and quality of life have also changed, and the disabled rightfully desire full participation in as many aspects of society as possible.

Although much has been added over the last decade, the systems of rehabilitation and care for the disabled are still developing in Singapore. Many of the basics are in place, including medical rehabilitation units at the acute hospitals, rehabilitative therapy programs at the community hospitals,

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day rehabilitation and daycare centers, nursing homes, as well as some home-based rehabilitation. However, issues that still need address include changing the older generation's perceptions on the importance of rehabilitation towards self-independence, rather than merely relying on the daughter-in-law, unmarried daughter, or the maid (foreign domestic worker). It also includes discrimination towards the disabled, accessibility, lack of transportation, vocational, educational, recreational, and possibly insurance programs for rehabilitative and long-term care.

The family practitioner may be presented with a sick patient in the clinic whose problems go beyond the medical. It will be useful to have a good understanding on the assessment process, rehabilitation principles, options and services available, as well as the coping strategies of patients and families with disabilities.

REHABILITATION⁶

Restoring function

There are various definitions of Rehabilitation, but ultimately the goal of optimal rehabilitation is to restore as maximal a functioning as possible under the circumstances/ limitations posed by residual impairments and the environment.

The International Classification of Impairments, Disabilities and Handicaps (ICIDH): World Health Organisation, 1980,⁷ is relatively dated but remains a simple and useful way to view areas for rehabilitation intervention. These terms have been replaced by Impairments, Activity Limitations, and Participation Restrictions, with the addition of contextual factors in the ICIDH-2, 2001 to address development in healthcare philosophies on the management of chronic illness and disability, particularly functioning within society.

Although the terms impairment, disability and handicap are often used interchangeably, they actually differ. It is useful to think of a continuum and how one affects the next. The terminologies in italics added are not part of the classification as such but help to complete the picture:

- i) Disease, Pathology, or Injury
- ii) Impairment: Any loss or abnormality of psychological, physiological or anatomical structure or function.
- iii) Disability: Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
- iv) Handicap: A disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.

Thus, diabetes can lead to a stroke (disease, pathology), resulting in hemiplegia (impairment), affecting ability to walk (disability), preventing easy access to a non-lift landing flat for this wheelchair user (handicap).

Rehabilitation would hence include management of the diabetes by the rehabilitation physician, therapies to strengthen and improve control of the hemiplegic arm, trunk and leg, and assisting with discharge to a lift-landing home or teaching a different technique of descending steps, e.g. in a seated position.

Benefits of Rehabilitation

Rehabilitation results in fewer complications, better functional outcomes, a better quality of life and lower medical costs. Patients/ families who have received rehabilitation are typically more aware of characteristics of the illness, and how to better take care of themselves. They have better mobility, ability for activities of daily living, and are more reintegrated into their surroundings and society. Complications get recognised and taken care of sooner and at earlier stages. Long-term rehabilitation follow-up minimises functional deterioration and maximises potential for functional improvement.

Examples of patients who can benefit from Rehabilitation

Neuro-rehabilitation:

- Stroke
- Spinal Cord Injury (traumatic, tumor, ischemic)
- Brain Injury (traumatic, tumor, anoxic, infective)
- Neurological Dysfunction (e.g. Multiple Sclerosis, Parkinson's Disease, Guillain-Barre Syndrome)

Musculoskeletal Rehabilitation:

- Amputation (lower limb, upper limb)
- Arthritis (degenerative, inflammatory)
- Orthopedic (fractures, soft-tissue injuries, joint replacements)

Others:

- Deconditioning (medical and post-surgical)
- Pulmonary (COPD, infective, transplants)
- Cardiac (myocardial infarction, bypass surgery, transplant)
- Chronic Pain (back, others)

The Rehabilitation Team

Some patients require comprehensive multidisciplinary rehabilitation intervention. This multidisciplinary team is commonly led by the rehabilitation physician, and includes the rehabilitation nurse, physiotherapist, occupational therapist, speech therapist, and medical social worker. The neuropsychologist may be involved, as may the prosthetist, orthotist, clinical pharmacist, dietician, vocational rehabilitation specialist, and medical equipment salesperson. In the US, there is also the kinesiotherapist, therapeutic recreation specialist, child-life specialist, music or dance therapist, etc.

Principles of Comprehensive Multidisciplinary Rehabilitation

- i) Rehabilitation physician-led team approach
- ii) Intensive, goal-oriented treatment
- iii) Towards functional independence

The Rehabilitation Physician

- i) Physician specialising in physical medicine and rehabilitation or physiatry, is sometimes known as a “doctor for the disabled”
- ii) Has special training in diagnosis and management of issues and complications relating to immobility, impairment and disability
- iii) Treats a wide range of problems from sore shoulders to strokes and spinal cord injuries, all age groups, all major body systems
- iv) Focuses on restoring function to people

The rehabilitation physician also receives training in principles of therapeutic exercise, physical modalities (heat, cold, electrical, traction, etc), prosthetics, orthotics, durable medical equipment, gait analysis, diagnostic and therapeutic injections, urodynamics, electrodiagnosis (EMG/NCS), and comprehensive rehabilitation team management.

Referrals to Rehabilitation Medicine

- i) Patients with functional deficits, e.g. difficulty with swallowing, speaking, transferring, walking
- ii) For management of complications of immobility or chronic disease, e.g. bowel and bladder dysfunction, contractures, spasticity, neuropathic and musculoskeletal pain
- iii) Need for expert assessment for comprehensive management, assistive and other devices, e.g. special wheelchairs, braces, prostheses

Clinical Services of a Rehabilitation Medicine Department

- i) Provides comprehensive, multidisciplinary, intensive, goal-oriented, inpatient rehabilitation for patients with potential for significant functional gains, towards an optimal level of independence
- ii) Consultation service to other departments and doctors to assess and recommend level of rehabilitation needed and options available
- iii) Specialist outpatient clinics to follow-up discharged patients, and new referrals for patients with functional deficits needing therapeutic exercise, modalities, orthotics or prosthetics, wheelchairs and assistive equipment
- iv) Performs procedures such as urodynamics, electrodiagnostics tests, soft tissue and joint injections

Good Candidates for Comprehensive Inpatient Rehabilitation

- i) Medically stable, e.g. afebrile, disease or injury work-up completed, resolved or adequately managed
- ii) Presence of persistent functional deficits, typically two or more, e.g. in self-care abilities, bladder/bowels,

swallowing, communicating, transfers, locomotion (single disabilities may not need the entire rehabilitation team/multidisciplinary program)

- iii) Physical endurance adequate to participate actively in rehabilitation to some extent
- iv) Cognition and motivation adequate to learn, and to carryover what was learnt in previous sessions (i.e. not forgotten right away)
- v) Achievable rehabilitation goals

Guidelines for Inpatient Rehabilitation⁸

Assessment

Initial assessment includes: neurological and musculoskeletal deficits, medical co-morbidities, cognitive, emotional deficits, speech-language disabilities. Also look for impediments to community reintegration such as the living environment (e.g. lift to home level), family dynamics, community supports.

Continuity of care

The rehabilitation patient typically goes through multiple settings during the course of recovery, e.g. acute care -> inpatient rehabilitation -> outpatient/home rehabilitation. Hence, transfer of clinical information from stage to stage is important.

Patient and family involvement

Rehabilitation involves not only the patient but also the family. They need to be informed and involved in decisions, including selection of rehabilitation setting, goals and interventions, discharge disposition.

Support and Education

Emotional support, education, and counselling as to main features of the disease/surgery including cause and manifestations, treatment, and prognosis are initiated. Once again, patient and family involvement are intrinsic to the rehabilitation program.

Discharge planning

The post-discharge setting needs to be decided on early in the rehabilitation process as it forms an important part of the goal. Caregiver training may be needed and also the training on assessment of equipment needs, e.g. a wheelchair. Continuity of care should be ensured.

What Happens during Comprehensive Inpatient Rehabilitation

Initial Assessment and Management:

When the patient is first transferred to Rehabilitation Medicine, a detailed assessment is done and immediate issues are managed including swallowing and communication, bladder and bowel

management, nutrition, hydration, and skin breakdown. The medical, physical, psychological, socio-economic, and functional abilities of the patient are also assessed.

Therapy and Education of Neurological/Musculoskeletal Condition:

Therapies for motor strengthening, sensory re-education or compensation, balance and posture restoration, coordination drills, strategies to improve or compensate for visual-spatial and cognitive deficits are instituted. The education and training process into the disability and rehabilitation plan are started.

Compensation Strategies:

Frequently, there are severe or permanent impairments that may require modified sequences or strategies to carry out a previously routine functional task, e.g. donning of clothes. Equipment may also be used to compensate for the impairment including prostheses, orthoses, and mobility devices such as wheelchairs and walking aids.

Management of Complications:

The patient is at risk for complications that have to be managed on the rehabilitation unit such as skin breakdown, spasticity, contractures, venous thromboembolism (DVT and PE), musculoskeletal and neurogenic pain, depression, autonomic dysfunction, reflex sympathetic dystrophy, infections especially pulmonary and urinary, seizures, falls, malnutrition, cardiac events, and recurrent stroke.

Discharge Planning:

Planning is done early on for discharge destination and post-discharge care. Continuity of care may include arrangements for follow-up therapy and subsequent outpatient care. The patient may need a home visit and recommendations for renovations/modifications. Avocational (recreational) issues are important for quality of life. Vocational issues are relevant in some patients and may involve liaison with the employers, workplace adaptations, and job retraining. Other adjustments that may need attention are sexuality, issues of self-worth, and identity.

Stratification for Rehabilitation⁸

Medically unstable

Generally not suitable for an active rehabilitation program, but may benefit from passive rehabilitation including maintaining range of motion and avoidance of complications such as pressure sores.

Medically stable with complex medical and rehabilitation issues

Hospital inpatient rehabilitation facility with full-time rehabilitation physicians, nurses, a full complement of therapists, and availability of other medical specialists.

Moderate to severe disabilities

Intensive inpatient rehabilitation program if tolerating three hours of intervention and physical activity per day; and if unable, less intensively in a community hospital, extended care facility, outpatient facility, or home-based rehabilitation.

Supervision or minimal disabilities, unable to live independently

Home-based or outpatient rehabilitation if home environment and support adequate; inpatient hospital or nursing facility if not.

Mild disabilities, able to live independently

Has difficulty with complex activities such as housekeeping, meal preparation, public transportation, leisure activities or return to work. May benefit from rehabilitation services targeted at the problem areas, either as outpatient or home-based. If inadequate home support, may need a supervised living setting such as a sheltered home.

Rehabilitation Prescription

In rehabilitation medicine, the prescription goes beyond medications for the disease or surgery for the injuries. The rehabilitation physician also has ability to prescribe therapeutic exercise, modalities of various forms, types and specifications of prosthetics, orthotics and other equipment.

Therapeutic Exercise

There are various types of exercise including Active (done by patient), Active-assisted (partially done by patient, assisted by therapist/helper), or Passive (done by therapist/helper). It may also be Isotonic (either Concentric or shortening exercises, and Eccentric or lengthening exercises), Isometric (static or non-shortening exercises), or Isokinetic (constant velocity or accommodating resistance exercise). Open kinetic Chain (force adequate to overcome resistance, e.g. leg-press, cycling) and Closed kinetic Chain (force not great enough to overcome resistance, e.g. squats, running), Aerobic and Anaerobic, Power and Endurance-building, Strengthening and Fitness exercises. Low-repetition, high-resistance exercise produces Power, whereas high-repetition, low-resistance exercise produces Endurance. Specificity Training is another consideration - exercising muscles of ambulation are important, but it is still necessary to work on actual walking to best regain this function. Other aspects of exercise may include restoring balance, posture, crutch and cane usage, wheelchair skills, and gait retraining.

Heat Modalities

Heat may be delivered via hot packs, paraffin wax bath, fluidotherapy, infrared radiation, shortwave diathermy, and ultrasound. Thermal properties include that of analgesia and sedation (decreases pain and spasms, aids relaxation, general stimulant). Improved blood flow increases nutrient inflow and

waste removal. Increased non-elastic tissue extensibility allows elongation/stretching of tendons or scars with increased range of movement.

Cold Modalities

Cold may be delivered through ice massage, chemical cold packs, ice towels, ice packs, or vapocoolant sprays. Cold has thermal properties of analgesia/sedation, ability to decrease pain, spasms, and aids relaxation. Decreased peripheral nerve activity may reduce spasticity. Lower joint tissue and fluid temperature decreases activity of enzymes that may damage the joint.

Hydrotherapy

Swimming pool or whirlpool tub hydrotherapy allows delivery of hot or cold treatment modalities. Buoyancy, hydrostatic pressure, surface tension, cohesion, and turbulence create an environment for therapeutic exercise including muscle strengthening, balance, range of motion activities, and reduced-weight ambulation. Thermal properties and hydrostatic pressure improves circulation and reduces oedema.

Pressure, fluidity, and turbulence are useful for skin problems and open wounds, including debridement, removal of dressings, application of medications or lubricants. Hydrotherapy is also relaxing and produces psychological benefits.

Electrical Stimulation

Direct stimulation of spastic muscles, antagonistic muscles, or reciprocal stimulation of both decreases spasticity. Use of electrical stimulation to increase circulation and nutrition to denervated muscle is controversial as it retards atrophy, but may interfere with peripheral nerve regeneration. It decreases oedema by improving circulation with muscle-pumping action.

Iontophoresis

Uses electric current to drive ions of medications through skin into the underlying tissue. Substances or medications include steroids, lidocaine, salicylate, zinc oxide.

Transcutaneous Electrical Nerve Stimulation (TENS)

Application of low-voltage electrical pulses to nervous system through the skin may change pain perception as per the Gate-Control Theory whereby high-frequency stimulation of nonnociceptors or A-beta axons interferes with relay of pain sensations to higher brain centres. TENS may also be effective via natural opiates from the pituitary gland (beta-endorphins) and spinal cord (enkephalins) released by low-frequency stimulation of A-delta sensory nerves.

Ultraviolet Irradiation (UV)

UV produces vasodilatation that stimulates granular tissue formation leading to tissue repair. Bacterial destruction occurs from stimulation of reticuloendothelial cells, increasing circulatory antibodies, and associated wound healing promotes tissue growth.

Light Amplification by Stimulated Emission Radiation (LASER)

Low-powered Helium-Neon lasers of 1 mW or less have effects that include pain reduction and accelerated tissue healing from increased collagen synthesis, vascularisation, and decrease in microorganisms. They may be used for promotion of tissue healing, and management of pain associated with muscle spasm, headaches, local and systemic inflammation.

Biofeedback

Gives immediate information returns about physiological functions, which allows active self-control over the function being monitored. It may be through aural or visual feedback, skin thermal feedback, skin electrical conductance, or electromyographic (EMG) feedback for muscle activity.

Traction/ Distraction

Application of forces to the spine or limbs separate vertebrae and elongate surrounding tissues such as muscles and ligaments, increase space between vertebrae, articulating facets, and intervertebral foramen. This may result in relaxation of paraspinal muscles, improved blood circulation and diminution of bulging herniated discs or pressure on nerve roots in the intervertebral foramen.

Intermittent Pneumatic Compression

Pumps can be utilised to intermittently force air into inflatable sleeves or boots around an upper or lower extremity. Resultant increased interstitial space fluid pressure encourages fluid return to the venous or lymphatic vessels, improving circulation and helping control/reduce oedema.

Orthoses (Braces)

Orthoses may be used for the upper limb, lower limb, neck and back. Upper limb braces include resting hand splints, e.g. for carpal tunnel syndrome, functional splints to allow immobilisation of affected joints yet maintain hand function, and corrective splints, e.g. those that ostensibly “pull back” contractures. Lower limb splints include the ankle-foot-orthosis (AFO), that may also be used for resting/ positioning/ protecting the ankle (e.g. pressure-reducing AFO), for function (walking AFO, sole to patella-tendon weight-bearing displacement AFO), or corrective (tone-reducing AFO). Many braces are available for the knee such as the straight canvas, articulated free-angle knee, elastic knee braces, and adjustable-angle braces. The neck orthoses include the Halo, SOMI (sterno-occipital manibular immobiliser), 4-poster, stiff collars such as the Aspen and Philadelphia, soft-neck braces. Back braces include the plastic body-jackets, the CASH (cruciform anterior spinal hyperextension), and Jewett contra-flexion brace.

Prostheses

Upper limb prostheses include the below-elbow (or trans-radial) and above-elbow (trans-humeral), but are relatively uncommon

due to lower frequency of upper limb amputations compared to lower limb. In addition, there are issues of prosthetic acceptance and functionality that lead to rejection of these replacement limbs. Lower limb prostheses on the other hand are much more prevalent, although these also have a significant rate of rejection or non-use after fabrication. These include the common below-knee (trans-tibial), above-knee (trans-femoral) prostheses, as well as the less frequent Syme's, through-knee, and hip-disarticulation prostheses.

Equipment

The proper prescription of a wheelchair takes into consideration the patient's needs such as whether electric or manual, lightweight or regular, fixed or removable arm rests and leg-rests, pneumatic versus hard rubber tires, and other specifications and components. The patient's functional ability may depend on a properly prescribed and sized wheelchair with an appropriate foam, air, or gel cushion. Assistive devices for ADLs include reachers, large-handled utensils, and other adaptive devices for self-care. Walking devices include walking frames, quadrilateral canes/sticks, axillary or forearm crutches, walking canes. Assistive technology such as voice synthesisers and environmental control units may be prescribed.

Medications Common in Rehabilitation

- i) Spasticity: Baclofen, diazepam, gabapentin, tizanidine, carisprodol, cyclobenzaprine, orphenadrine, botulinum toxin
- ii) Autonomic dysreflexia: Topical lidocaine, nifedipine, nitrates (nitroglycerine paste), propranolol, and also phenoxybenzamine, terazosin, diazoxide, hydralazine
- iii) Neuropathic pain: Amitriptyline, nortriptyline, trazadone, gabapentin and pregabalin, carbamazepine, also baclofen, tizanidine, clonidine, mexiletine, lidocaine, capsaicin
- iv) Depression: Fluoxetine, fluvoxamine, sertraline, escitalopram, mirtazapine, amitriptyline, nortriptyline
- v) Psycho-modulation including neurostimulants, suppressants and sedatives: Methylphenidate, amantadine, bromocriptine, valproate, propranolol, quetiapine, risperidone, haloperidol, lorazepam, also chloral hydrate, zolpidem,
- vi) Bladder management: Tolterodine, oxybutinin, baclofen, terazosin, tamsulosin, finasteride, also propantheline, amitriptyline, flavoxate, ephedrine, bethanecol, prazosin,
- vii) Bowel management: Psyllium, isphagula, lactulose, senna, bisacodyl, also docusate, glycerine, and paraffin.

COPING WITH DISABILITIES

The process of coping with disabilities is different for an adult than for a child. The child has to contend with issues of growing up (physically and mentally), and development of functional or social skills and relationships. The adult presumably has already attained these and the challenges of coping include loss or changes to previously intact abilities, life-roles, and yet-to-be achieved life goals. The process will again vary depending on

the age, as a young adult might have concerns about his family and providing for their future, whereas the elderly might have greater concerns about abandonment and death.

An understanding of the processes and issues involved in coping with disabilities will help equip the medical practitioner to better provide practical and emotional support, as well as possible strategies to patients.

Changes with Disability

Following the event causing the acquired disability, the patient may have changes in different areas:

Physical changes

- i) Mobility may be affected and ambulation is either with difficulty or an abnormal gait, and the patient may require a wheelchair.
- ii) Self-care ability is often affected or there may be safety concerns, e.g. fall risk, or it takes significantly more time to perform it.
- iii) Where the patient may have previously been very articulate, speech disabilities could now produce the opposite picture.
- iv) Loss of bowel, bladder, and swallow function requiring diapers, urine and feeding tubes.
- v) There may be actual changes in the patient's anatomy and body appearance from the trauma or disease. Prostheses may look unnatural and be a problem from a cosmesis viewpoint.

Psychological changes

- i) Emotional changes are common and include anger, grief, depression, guilt, anxiety, fear, stress, dysphoria, etc.
- ii) Changes in life-role may take place, viz. that of being the bread-winner, home-maker, decision-maker, husband or wife, father, mother, son or daughter.
- iii) Changes in body-image and loss of self-esteem, from that of a fit, "normal" person to now possessing paralysed, possibly deformed or atrophied limbs and body.
- iv) Loss of dignity, and embarrassment with incontinence of bowel and bladder functioning – even the fear of this occurring may be psychologically paralyzing.
- v) There may be turning towards unhealthy means of coping, including development, or exaggeration of a pre-existent problem of chemical addiction including to alcohol and drugs.

Cognitive changes

- i) Executive function may be impaired with deficits in problem-solving ability, good evaluation and judgment skills, memory.
- ii) Ability to concentrate, proper attention spans, and delay in processing speed of information.
- iii) Language may also be affected, over and beyond speech difficulties
- iv) There may be behavioral issues with personality changes, unusual impatience, impulsivity, and easy agitation.

Other changes

- i) Responsibilities and relationships: With family, friends, socially and vocationally.
- ii) Society and the environment: This includes acceptance of the patient's newly acquired disability by the employer due to concerns regarding ability to perform, medications, and time-off for medical appointments. Other challenges may include social isolation, transportation difficulties, public curiosity (staring, commenting), stigma, and disempowering language/ terminologies ("crippled by"), paternalism, over-protectiveness, and control issues.
- ii) Financial and Legal: There may be a need for the family/ state to take Power of Attorney for medical and financial decisions. Other issues include Workers' Compensation disputes, critical illness and disability insurance, and pending litigation. There may be concerns about loss of income, taxes, medical costs, housing needs, equipment and homecare costs.

Adjustment Dynamics⁹

Patients go through an adjustment process following a new disability or loss that includes several if not all of the stages below. Although there may be fluctuating between stages and even a return to a previous stage after seemingly being past it, ultimately most do attain the goal of adequate coping. The patient also has to contend with varying stressors over time and may ultimately have to cope with the aging process coupled with a disability.

- i) Shock (denial, bargaining, fear of realities and implications)
- ii) Partial acceptance (of some realities)
- iii) Depression (inward)
- iv) Anger (outward)
- v) Coping (recognise and accept limitations, make the best possible)

Coping Skills Model¹⁰ (based on Crisis Theory, Lindemann E, 1944)

Although variable from individual to individual, patients may adopt some or all of the following coping models:

- i) Denying or minimising seriousness of crisis
- ii) Seeking relevant information
- iii) Requesting reassurance and emotional support
- iv) Learning specific illness-related procedures (e.g. rehabilitation therapy)
- v) Setting concrete limited goals
- vi) Rehearsing alternative outcomes
- vii) Finding a general purpose, or pattern of meaning, in course of events

Reaction to Disabilities¹¹

As before stated, there is tremendous individual variability in response to having acquired a disability. It has been proposed

that a Rule of Thirds applies to coping:

- A third cope very well due to previously established skills, personality traits, and support of significant people in their lives
- Another third have greater difficulties, but with minimal professional or psychotherapeutic assistance, are able to successfully get through the crisis
- The last third however, have significant coping difficulties, may require a large amount of professional intervention, and often have a history of adjustment issues, e.g. chemical abuse, mental disease, with a low tolerance for imposed structure and limitations.

Healthy Coping

There are many strategies and philosophies for coping with adversities in life, and a guiding principle should be that each person is different - what may be effective for one may not be for another. Nevertheless, at each level there are strategies that may be helpful:

- i) Personal
Acknowledgment/acceptance of loss, express grief, sharing, keep interested in life, humor, exercise, massage, meditation, relaxation, patience, perseverance, tolerance
- ii) Family and Friends
Support system, listening, encouragement, unconditional acceptance, affirmation
- iii) Professionals
Treatment, interventions, information, encouragement, psychotherapy, medications, coordination, resources.
- iv) Peer Support Group and Counseling
Mutuality of situation, understanding, support, forum for expression, sharing information
- v) Religion and Personal Beliefs
Faith, strength, peace, tranquility, hope

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LEARNING POINTS

- **The goal of optimal rehabilitation is to restore as maximal a functioning as possible under the circumstances/ limitations posed by residual impairments and the environment.**
 - **Benefits of rehabilitation include fewer complications, better functional outcomes, a better quality of life and lower medical costs.**
 - **The rehabilitation team led by the rehabilitation physician is multidisciplinary, providing intensive, goal oriented treatment working towards functional independence.**
 - **Patient and family involvement are intrinsic to rehabilitation programmes.**
 - **Caregiver training may be needed, as does assessment of equipment needs, e.g. wheelchair. Continuity of care should be ensured.**
 - **An understanding of the processes and issues involved in coping with disabilities will help equip the medical practitioner to better provide practical and emotional support, as well as possible strategies to patients.**
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UNIT NO. 6

ASSESSMENT OF THE SIX ACTIVITIES OF DAILY LIVING IN ADULTS

Dr Ng Yee Sien, Dr Heeyoune Jung

ABSTRACT

The assessment of disability including activities of daily living (ADL) is important as a clinical tool to document functional recovery as well as to assess the effectiveness of medical and rehabilitation interventions. Disability assessment is also important epidemiologically, in developing social policies, planning disability resources and in medical research and education. In this article, we review the definitions, history and advances in the field of disability assessment. We then describe the general principles of disability assessment in adults with a further detailed focus on six basic ADLs: feeding, bathing, dressing, toileting, transfers and mobility. We use a practical framework of an independent category and four dependent categories corresponding to an increasing level of assistance for each ADL. Finally we summarise the inherent problems and difficulties in disability assessment and emphasise the important role of rehabilitation in improving functional outcomes including the basic ADLs.

Keywords: Disability assessment, disability assessment tools, dependency, eating, bathing, dressing, toileting, transfers, mobility.

SFP2012; 38(2): 32-40

INTRODUCTION

Disability or activity limitation is defined as a restriction or lack of ability to perform an activity, including ADLs as a result of an impairment, or loss of body structure or function^{1,2}. The prevalence of disability in Singapore is rapidly increasing for two major reasons. Advances in acute medical care result in a larger proportion of patients with chronic diseases surviving with residual impairments and disability. In addition, the ageing of the population also results in the exponential increase of the disability burden due to the direct association of increased chronic disease incidence with the more elderly³. However, it is a common misconception that disability only occurs in the elderly and preliminary local data indicates there is a large number of disabled younger adults as well, particularly with stroke, spinal cord and traumatic brain and musculoskeletal injuries⁴.

Disability results not only in individual loss of self-esteem and quality of life, but also increases tremendously the social

and financial burdens of their involved families, society and the country-at-large. Families need to adjust their expectations and care for the disabled, resulting in changes in family routine and activities, as well as often a loss of income as a direct or indirect consequence of loss of time available for remunerative employment^{5,6}.

The aim of this article is to provide an overview of the disability determination of ADLs, focusing on the assessment of six ADLs that are crucial for self-care.

OVERVIEW AND FRAMEWORK OF DISABILITY ASSESSMENT

The need for accurate determination of disability arose in the early 1900s during the industrial revolution whereby a worker sustaining a work-related injury resulting in a medical impairment which affected his employability could seek redress from the courts⁷. This led to the development of workers' compensation systems in many countries, and the Ministry of Labor in Singapore has recently released updated guidelines⁸. Accurate determination of disability became essential because of the direct correlation between the degree of disability and quantum of financial remuneration common in these guidelines.

The further need and development of disability assessment moved in tandem with the exponential increase in medical knowledge as well as a worldwide change in disease profile in developed countries from one of infectious disease and death, to chronic disease and disablement. Singapore shares a common trend with most developed countries whereby the principal causes of morbidity and mortality (accounting for more than 80%) are non-communicable diseases including cancer, coronary artery disease, stroke, diabetes, hypertension and injuries⁹. This has led to spiraling health care costs for health-care systems and governments for managing both the disease itself, and the costly burden of managing the consequence of disability. The current urgent need for disability assessment could be summarised thus^{1,10}:

1. Epidemiologic data in population studies and to establish the extent of disability burden.
2. Clinical tool, both to measure baseline disability, the natural recovery of chronic disabling illnesses, as well as to assess the effects of the wide array of medical and rehabilitation interventions available on disablement.
3. Research tool for outcome measurement and factors that impact on disability.
4. Social policy instrument in planning for health care funding, insurance systems and formulation of health-care policies
5. Educational tool in medical school curriculum design, as well as for advocacy and the raising of social awareness of the disabled.

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The World Health Organisation (WHO) has recognised this need and continually develops conceptual disablement models for international acceptance and use, and these frameworks are employed in the development of various disability measures. The International Classification of Impairments, Disabilities and Handicaps (ICIDH) developed by WHO in 1980 describes consequences of disease and disablements and is still used in the American Medical Association Guides to the Evaluation of Permanent Impairment (AMA guides)^{2,11}. The International Classification of Functioning, Disability and Health (ICF) developed in 2001 focuses on the components of health rather than the consequence of disease and further recognises the important role of the environmental factors which may include human and technological social support systems which impact on health¹. In addition, a comprehensive hierarchical coding system which includes codes for body structures and functions, various ADLs and the severity of the disablement are described, and these codes can be expanded to great detail allowing for further development. The ICF has been adopted by more than 190 countries throughout the world and its key elements have been incorporated into various disability assessment scales for use by clinicians and administrators involved in healthcare.

CURRENT DISABILITY ASSESSMENT TOOLS

Using definitions from the ICIDH and ICF models, the assessment of disability involves strictly the assessment of the severity of activity limitation including ADLs, and not the assessment of the severity of loss of body structure or function (or termed impairment in the older ICIDH model)^{1,2}. For example, in the common scenario of a patient who has a left middle cerebral artery stroke resulting in a right hemiparesis, it is not an assessment of degree of loss of strength of the right arm (loss of body structure/function), but an assessment of the amount of assistance a subject requires to dress himself or groom himself because of the loss of strength in the right arm (activity limitation). This is important conceptually because the loss of body structure/function or impairment may not correlate to disability and activity limitation and it is the severity of disability that is far more important in the determination of caregiver and societal burden¹².

Unfortunately, there is no consensus in the rehabilitation or geriatric literature as to what constitutes the core group of ADLs that need to be measured. However, most authorities and texts agree that ADLs can be divided into the following¹³:

1. Basic ADLs (BADL). These can include some or all of these activities deemed critical to basic self-care:
 - i. Self-care: Eating, Grooming, Bathing, Dressing, Toileting.
 - ii. Continence: Bladder and Bowel Continence
 - iii. Mobility: Transfers (for example bed to chair, chair to toilet seat), Walking or Wheelchair Use, Climbing Stairs
 - iv. Cognition: Communication including Comprehension, Expression, Memory and Simple Problem Solving.

2. Instrumental ADLs (IADL) or Extended ADLs (EADL) This list is long, but generally involves more complex activities such as food preparation, medication use, telephone use, transportation use, housekeeping and laundry.

3. Community Reintegration and Participation Activities These form the highest tier of activities in daily living and include employment, leisure activities, and various recreational activities.

Instruments exist that measure any or all of these three categories of ADLs. For the purposes of this discussion, we focus only on tools that measure BADL as these have the most direct and significant impact on caregiver burden. BADL assessment is also directly relevant in the disability assessment for the disability-related national schemes (DRNS) locally including ElderShield/ Interim Disability Assistance Programme for the Elderly (IDAPE), Dependants' Protection Scheme (DPS), Community Health Assist Scheme (CHAS), [formerly known as the Primary Care Partnership Scheme (PCPS)] and the Foreign Domestic Worker (FDW) Levy Concession.

There are only two major BADLs scales of disability used consistently throughout the world presently and these are the Barthel Index (BI) and the Functional Independence Measure (FIM), both of whom have undergone modifications and revisions over time¹⁴⁻¹⁷. Both these scales also have good test-retest and interrater reliability, content validity for the measurement of disability, and are sensitive to changes over time¹⁷. Importantly, there is a direct correlation between the severity of disability and the amount of care required¹²⁻¹⁸. The BI has the following items: eating, grooming, bathing, dressing, toileting, maintenance of bowel and bladder continence, transfers and locomotion. The more recently developed FIM has similar items to the BI, but further include items on cognitive BADLs such as communication skills, problem solving and memory. This reflects principles explored in the ICF that these cognitive BADLs are not only essential to everyday living and can impact on the better-known physical BADLs^{1,16}. The BI and the FIM have shortened versions which are also valid and reliable in measuring BADLs¹⁹. Similarly, the current DRNS including ElderShield/ IDAPE, DPS, PCPS and the FDW Levy Concession employ selected BADL items in self-care, continence and mobility above and these items are essentially part of the BI and FIM.

DISABILITY ASSESSMENT: GENERAL PRINCIPLES OF DISABILITY ASSESSMENT

(In the subsequent discussion that follows, ADL is synonymous with BADL)

We provide a general applicable framework for the subsequent discussion on disability assessment (Figure 1 and Table 1). Our aim is to illustrate the key concepts of disability assessment rather than follow any particular disability scale. Throughout, we advocate the use of the terms dependence and amount of

assistance rather than terms indicating the amount of ability in each ADL (Table 1). This is because the aims of disability assessment used in the original (including the WHO-ICF, BI and FIM instruments) and usual contexts is to correlate to the burden of care required^{1,12-18}.

Each ADL is first categorised into an independent versus dependent group (Figure 1). This dichotomisation is critical and this distinction is consistent in the disability assessment literature¹²⁻¹⁸. **Independence** is the performance of an ADL without the need for a helper regardless of whether aids (such as modified eating utensils or walking frames) are used.

Dependency is defined as the need for assistance from a helper and so, indicates presence of caregiver burden.

Total assistance or disability is clearly distinct in disability assessment. The degree of disability and the categorisation of amount of assistance between the two extremes of independence and total dependence however are subjective. The continual refinement and advancements in disability assessment aim to improve the objectivity in assessing these shades of grey²⁰.

In this article, we group each ADL into four generally accepted dependent categories for ease of discussion. In summary then, we have one independent and four dependent categories (Figure 1 and Table 1) for the discussion that follows¹²⁻¹⁸.

These are:

- 1. Independence: No helper or assistance required.
- 2. Dependent: Minimal Assistance: Subject does 75% or more of the ADL.
- 3. Dependent: Moderate Assistance: Subject does 50 to 74% of the ADL.
- 4. Dependent: Maximal Assistance: Subject does 25 to 49% of the ADL.
- 5. Dependent: Total Assistance: Subject does less than 25% of the ADL.

General principles follow:

- 1. Assess and score what the subject actually does, and not what the subject can do.

It is important to differentiate between capacity (what the subject can do) and performance (what the subject actually does). This is because performance and not capacity determines caregiver burden.

Table 1. Summary and Comparison Chart of Indices of Disability Assessment in Adults

Terms and Definitions in this Article Text		Detailed Definition based on Amount of Assistance*	Definition based on Ability*	Arranged from latest → earliest time of development**				
Percentage of ADL Performed	Definition based on Amount of Assistance*			FIM +	MBI ≠	BI §	BI *	Katz #
All	Independent	Independent	Able	7	5	3	2	Independent
		Modified Independence		6				
All 75% or More	Minimal Assistance	Supervision	Partially Able	5	4	2	1	Dependent
		Minimal Assistance		4				
50 to 74%	Moderate Assistance	Moderate Assistance		3	3			
25 to 49%	Maximal Assistance	Maximal Assistance	Not good as not able	2	2	1		
Less than 25%	Total Assistance	Total Assistance	Not able	1	1			

* In general, definitions based on the amount of assistance are preferable compared to definitions based on ability. This is because the amount of assistance better reflects the amount of caregiver burden required and had been the original aims of most of the disability scales. This does not follow the Eldershiel categorisation strictly as it is intended rather to provide a conceptual correlation to other scales.

** Various widely-used disability scales arranged from latest to earliest time of development. Note that the numbers in the columns do not refer to the points scored, but the grouping of disability categories.

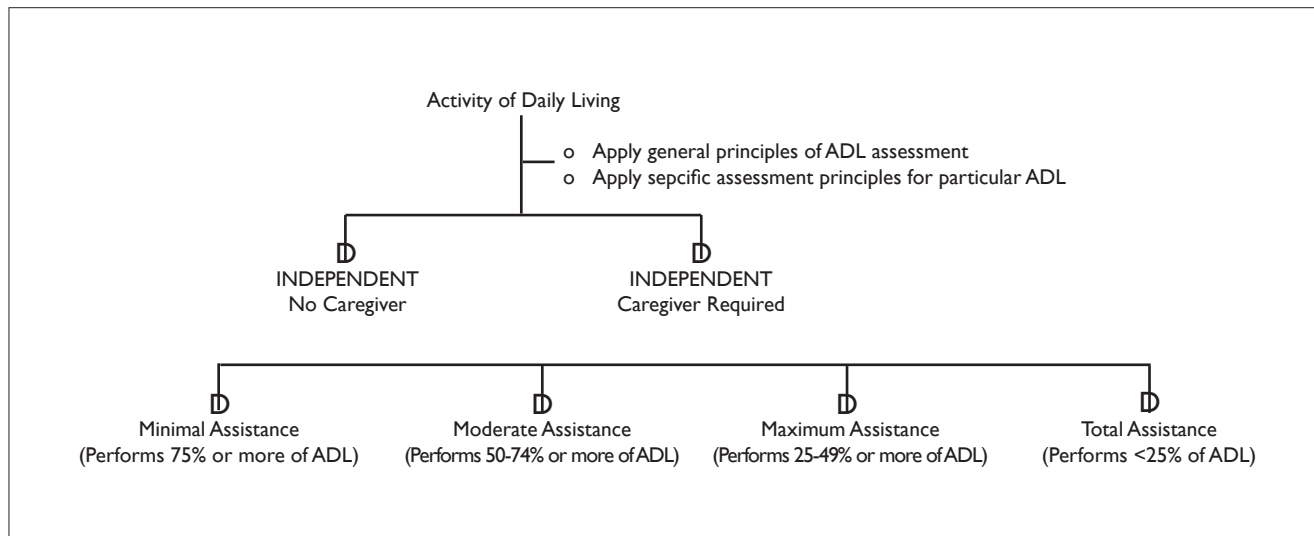
+ FIM: Functional Independence Measure. Note that the FIM categories correspond to the column 'detailed definition based on amount of assistance'. Each ADL is scored from 1 to 7.

≠ MBI: Modified Barthel Index. Each ADL is grouped in five disability groups, however the weightage is different for the ADLs. For example, eating and toileting points range from 0 to 10 points (0,2,5,8,10 points respectively) whereas transfers and ambulation range from 0 to 15 points (0,3,8,12,15 points).

§ BI: Barthel Index. ADLs for eating, toileting, dressing, bladder, bowel and stair climbing are grouped into three groups (0,5,10 points).

* BI: Barthel Index ADLs for toileting, bathing, and locomotion are grouped into two groups (0,5 points).

Katz Index of Independence in ADLs. The Katz Index simply dichotomises ADLs into independency or dependency and then groups all ADLs to give a summary group of A to G to determine the degree of disability.

Figure 1: General Schema of Disability Assessment for Each ADL for this Article Text

Examples are:

- i) Both cognitive/mental and physical impairments should be taken in consideration for each ADLs. In patients with dementia, they may be able to wear a shirt independently in front of an assessor (capacity), but are fully unable to do so at home because of memory impairment, severe apraxia or significant depression (performance). The subject should be scored as maximal or total assistance (performance).
- ii) A spinal cord injured patient with complete paraplegia may be able to propel a wheelchair more than 50 meters in a gym or a straight well-paved corridor. However, he is unable and does not want to do so at home because of multiple steps, small doorways or cramped confines of a single-room flat. He should be scored as maximal or total assistance (performance) because of the large caregiver burden required for household ambulation as part of his ADL.

2. Score the lowest or maximal assistance for that particular ADL if the performance on that ADL fluctuates¹⁴⁻¹⁷. This is to ensure a fair appraisal of the subject's performance and to reflect caregiver burden. Examples include:

- i) If a patient has severely impaired vision due to advanced diabetic retinopathy or cataracts, he may be able to transfer from bed to chair with minimal assistance in the daytime, but requires maximal assistance at night because of the high risk of falls. He should be scored as maximal assistance required for transfers.
- ii) If a patient has advanced rheumatoid arthritis of the hands and requiring maximal assistance in the morning in eating because of early-morning stiffness or fatigue, but subsequently performs better in the evening, he should be scored as requiring maximal assistance in eating.

3. If an ADL has more than one component, the lowest or maximum assistance required for a particular component is the score for the ADL. Examples include:

- i) If a patient with a stroke requires only minimal assistance with dressing of the upper body, such as wearing a shirt, but requires moderate assistance in dressing of the lower body, such as wearing of trousers, then the score should be moderate assistance in dressing.
- ii) Likewise, if a subject needs only minimal assistance to move from bed to chair, but moderate assistance from chair to bed, he should be scored as moderate assistance for transfers.

4. Supervision (no contact required) is considered minimal assistance. If two persons are required for an ADL, this automatically is scored total assistance.

5. If there is doubt in the scoring of a particular ADL, it is helpful to rephrase the question from 'how much can the subject perform' in that ADL to 'how much assistance from the caregiver' is required, as the major goal of the disability assessment is to determine caregiver burden.

PRACTICAL ADMINISTRATION OF DISABILITY ASSESSMENT: ASSESSMENT OF THE SIX ITEMS OF BASIC ACTIVITIES OF DAILY LIVING IN DETAIL

In this article, we focus on six core ADLs: eating, bathing, dressing, toileting, transfers and mobility. We use Figure 1 and the first two columns in Table 1 as the basis of the discussion that follows. We also arrange the six ADLs in order of difficulty consistent with prior disability assessment scales¹²⁻¹⁸.

In each ADL, decide firstly whether the subject performs the task independently or is dependent, and then determine the level of dependence.

FEEDING

Definition: Ability to feed oneself food after it has been prepared

and made available. The assessment begins when someone places the food within the reach of the patient^{14,16}. It involves the following subcomponents: cutting up the food into bite-size portions, bringing food to the mouth with the use of utensils, chewing and swallowing it safely. If a subject relies on other means of feeding, usually a nasogastric tube, then the assessment is how the subject administers the feeding himself.

Practical Points: First decide whether a helper needs to be present at all during the actual eating process to decide between independence and dependence. Amongst the six ADLs discussed, the amount of assistance is probably the most subjective for feeding. The final score needs to take into account the subcomponent with the most assistance needed.

Independence is then the ability to cut food, bring food to mouth, chew and swallow without a helper needing to be present. This is regardless if adaptive cutlery (for example long handled or built up forks and spoons) is used. If a subject feeds via a nasogastric tube, he must be able to pour the enteral feed down the tube independently. This usually requires an additional funnel to guide the feed down to the tube and he should hold the funnel independently together with the nasogastric tube.

Dependence means a helper needs to be present during the feeding process. The following are some useful guides. Minimum assistance implies that set-up in the eating process is required. This includes the helper opening containers, cutting meat, pouring liquids or helping the subject wear a cuff to hold utensils. The need for preparation of modified food consistencies such as a pureed or thickened diet would be considered minimum assistance. We would consider maximal assistance if the helper needs to scoop food onto a spoon repeatedly before the subject brings the spoon to his mouth. Examples of total assistance include the need to manually feed every mouthful or the need to check the mouth for residual food with each mouthful or the need to prompt safe swallowing with each swallow to prevent choking (for example the need to remind the patient to chin tuck and do a double swallow with each swallow).

Example: A patient has severe rheumatoid arthritis of hands. She needs assistance in cutting up food and opening containers due to restriction in hand dexterity. However, she can bring the food to her mouth by herself, chew and swallow safely any consistency of food. This would be considered minimal assistance. If however she has temporomandibular joint involvement and has a lot of pain in chewing and requires checking at every mouthful for residual food to prevent choking, this would be scored total assistance.

Other Points: Some texts consider independence of eating regardless of food consistency so long as the subject does not require a helper present¹⁶. We disagree as this represents a limitation of the swallowing component of eating and caregiver burden is present.

DRESSING

Definition: Ability to put on, take off, secure and unfasten upper and lower body garments. Garments will include prostheses (artificial limbs), orthoses (braces such as a thoracolumbar corset), and specialised garments which are deemed necessary for the patient, such as compression stockings for lower limb oedema. The patient should be assessed on clothing that he wears on a regular basis and of appropriate decency if he appears in public. We do not recommend that the wearing of undergarments and of footwear be considered as this complicates the assessment.

Practical Points: Divide the task first into upper and lower body dressing and score the amount of assistance required for each. Subsequently score the lower of the two scores as the ADL score for dressing. Lower body dressing is usually more difficult¹⁶⁻¹⁷.

Independence is then the ability to dress the upper and lower body completely without the need for an assistant. The subject may use aids such as a long-handled reacher to pull up his trousers if he is unable to bend his trunk.

Dependence means that a helper is required and may range from minimal assistance whereby a helper instructs verbally the steps required to put on clothes, or total assistance. If the degree of assistance becomes difficult to assess, we suggest dividing the garments in parts:

T-shirt: 3 parts: (1) thread the right sleeve, (2) left sleeve, and (3) pull it down the head and body.

Buttoned shirt: 4 parts: (1) thread the right sleeve, (2) left sleeve, (3) pull the shirt across the body, and (4) fasten (or unfasten) the buttons.

Shorts: 3 parts: (1) thread through the right leg, (2) left leg, and (3) pull the shorts up over the pelvis.

Buttoned or zipped trousers/pants: 4 parts: (1) thread through the right leg, (2) left leg, (3) pull the trousers/pants up over the pelvis, and (4) fasten (or unfasten) the buttons or zips.

Example: The stroke patient with a left hemiparesis wears a T-shirt and a pair of zipped pajama pants at home and in public. He is able to thread the left sleeve of the T-shirt with his good arm, but not the right sleeve of his T-shirt. He is however to pull the T-shirt over the head and down the body once the helper threads the right sleeve of his T-shirt for him. So for upper body dressing he performs in 2 out of 3 parts = 66.6% of the ADL = moderate assistance.

He is however not able to reach and thread the shorts through his right leg and left leg, but is able to pull up the pants over his trunk once it is threaded. He also needs help to pull up his zipper. For lower body dressing he performs only 1 out of 4 parts = does only 25% of the ADL = maximal assistance. His score for dressing would then be maximal assistance based on the lower score.

Other points: Garments, which are deemed necessary for the

patient's condition, are best scored as an able or not able situation. For example, a patient has been prescribed a rigid thoraco-lumbar orthosis for severe osteoporosis of the spine with compression fractures for prevention of further deterioration and is instructed to wear it. If he is unable to put it on himself, then this should be scored as total assistance, and the score for dressing will be total assistance regardless as to the score for wearing of the clothing.

Garments that are not absolutely necessary for the patient's condition, for example a sports-type knee brace that the patient wears for warmth and comfort for osteoarthritis of the knee, should not then be taken into consideration in the assessment for dressing.

BATHING

Definition: Ability to wash or bathe in a bathtub, shower, or sponge/bed bath. This has the three subcomponents of washing, rinsing and drying. For practical purposes, it is reasonable to assess bathing below the neck only.

Practical Points: Independence is then the ability to wash, rinse and dry the body without the need for a helper. This is regardless of whether the subject bathes himself in a tub, showers or does a bed-bath.

Dependence indicates the need for a helper. If the amount of assistance proves difficult to establish, we suggest dividing the body into ten parts. The ten parts are the left arm, the right arm, the chest, the abdomen, the front perineal area including the genitalia, the back perineal area including the buttocks, the left upper leg, the right upper leg, the left lower leg/foot and the right lower leg/foot. Note that portions of a body part will be considered as unable, so the ability to wash only half the chest is considered as the chest is not washed.

Example: A patient who has a dense left hemiparesis can only wash, rinse and dry his left arm and chest with his right arm. He is unable to wash his right arm, abdomen, perineal region and unable to reach both the lower limbs. He performs only 2 out of 10 required steps = 20% of the ADL performed = total assistance

Other Points: The back is excluded from bathing, else, healthy non-disabled people may be scored as disabled. Many people do not wash their back every day or use an assistive device like a long-handled sponge. A clearer picture of disability will result if the back is not included.

The face and neck is excluded because of two reasons. Firstly, in many of the ADL scales including the BI and FIM, washing the face and neck is a separate ADL assessment in grooming, and grooming may further include brushing the teeth, shaving and washing the hair. Secondly, washing the neck and the face has a fairly strong functional overlap with eating and the functional scores generally correlate. The aim of this particular ADL

assessment is to assess the disability in bathing in isolation.

Note that the definition of bathing includes wash, rinse and dry. The amount of assistance is often under-estimated because a subject may be able to wash, but has difficulty manipulating a towel to dry. This should be scored as unable to bathe in accordance to the general principles described above.

TOILETING

Definition: Ability to use the lavatory and manage bowel and bladder hygiene. It consists of four steps: (1) maintenance of balance, (2) adjusting clothing before using a toilet, (3) maintaining perineal hygiene and flushing the toilet, and subsequently (4) adjusting clothing after using the toilet. The definition remains the same if a bedpan or commode is used. If a bedpan or commode is used, then step (3) would be the need to clear the bedpan and commode as well.

By strict definition, do not take into account other aspects of toileting. This includes:

- Transferring from a bed or chair onto the toilet seat. This would be assessed under transfers.
- The actual bladder or bowel function including whether the subject is continent, leaks, soils the bed or uses a catheter. This is more correctly assessed under bladder and bowel continence.

By definition, it includes however:

- Maintaining the balance during clothing adjustment and the actual act of urination and defaecation.
- Perineal hygiene issues including using toilet paper to clean the perineum and the ability to flush the toilet or clear the bedpan.

If a subject uses a diaper, then the assessment includes the entire process of removing the diapers, perineal hygiene, putting on a new diaper, and discarding the old diapers.

If a subject is on a long-term indwelling catheter, do not assess the component of changing the catheter under toileting, as there is usually no caregiver burden involved. If a subject is on self intermittent catheterisation, then he should be assessed as per the definition of toileting given above.

Practical Points: To determine the level of assistance required, it is often useful to divide the ADL into four steps listed above. For ease of assessment, a part of a component that is not performed should be scored as not performed.

Independence: No helper required to perform all four steps.

Dependence: Minimal, moderate, maximal and total assistance would then be the inability to do 1, 2, 3 or all 4 steps described in the practical points above.

Examples: A bed bound severe stroke patient who requires a helper to change his diapers is assessed as total assistance. Another stroke patient who uses a bedpan can remove and put on his clothing but requires a helper to lift his pelvis onto a bedpan (balance), and clean his perineum and carry the bedpan away after use. This implies that he can do 2 out of 4 steps and this would be considered moderate assistance. If the same latter subject can only thread one leg during the removal and putting on of his pants, he would be considered as unable to do these steps as well. This would imply that he can do none of the four steps and this would then fall under the total assistance category.

Other Points: Not all disability assessment scales require the ability to flush the toilet or clear a bedpan¹⁶. We believe that this should be included in the definition for hygiene reasons.

TRANSFERS

Definition: All aspects of transferring from bed to a chair or wheelchair and back to a bed. This tests several skills including doing first a sit-up from a lying position, a sit to standing position, a weight or pivot shift and a controlled descent to a sitting position in another location.

Practical Points: The heights of the bed and chair are often different and the assessment should score the direction of transfer that comprises the most difficulty. In a hospital, the bed is often higher than the chair and it is more difficult to get back to the bed from a chair. In homes where mattresses are often placed directly on the ground (futon-styled beds) the opposite occurs.

Independence: To transfer from bed to chair and vice versa without the need of a helper. If in a wheelchair, then approaches, locks brakes, removes foot and arm rests and does a transfer often with a sliding board. Regardless, all these are done independently.

Dependence: Minimal assistance means requiring only coaxing, cuing or at most steadying assistance to guide the subject to transfer. If the body requires support during transfer, this indicates moderate assistance. If a lot of weight is required to support the body, or if the legs need to be supported as well, this would indicate maximal assistance. Total assistance means that one helper is insufficient to do the transfer or the subject is unable to transfer regardless of assistance.

Other Points: The act of transferring is basic and critical in ADL. Many of the other basic ADLs such as eating, bathing, toileting require an initial act of transfer to a sitting position prior to ADL performance. This importance is recognised in many scales including the BI and its modifications whereby a higher weightage is given to transfers compared to the ADLs¹⁴⁻⁵. In other instruments such as the FIM, there are three types of transfers including the transfer from bed to chair, transfer to a shower or a bathtub, and transfer to a toilet; and hence the ADL 'transfer'

is triple the weightage of other ADLs¹⁶. Transfer from bed to chair or wheelchair is often the most important, common and difficult, and hence this particular transfer forms the definition for this article.

MOBILITY

Definition: The act of walking, once in a standing position. If a wheelchair is used for mobility, assessment commences only from a seated position on a level surface. The distance that is considered significant is controversial (see other points below). For this article, we use a distance of eight meters as significant. This would be approximately the end-to-end distance between two HDB apartment rooms, or twice the length of an average size GP clinic.

Practical Points: Record the score with the mode of locomotion that the subject uses most often, either walking or wheelchair. The distance that is considered significant is the same for walking or wheelchair mobility. The discussion that follows applies for both forms of locomotion.

Independence: The ability to walk independently eight meters. This is regardless of walking aid used and the speed of walking. Common walking aids are a cane (single-point stick), quad (four-point) stick, forearm or elbow crutches, axillary crutches, and a walking frame (with or without wheels, the latter termed a rollator frame).

Dependence: Minimal, moderate and maximal assistance, all indicate that the subject is still able to walk eight meters, but a helper needs to assist. Minimal assistance indicates usually contact guarding and gentle guidance to prevent falls. Moderate and maximal assistance imply that the weight of the patient needs to be supported by the helper. The difference is that maximal assistance means supporting the body weight considerably and with difficulty. Total assistance indicates either (1) The patient is unable to walk, (2) The patient cannot cover eight meters regardless of the amount of assistance or (3) Two helpers are required. Points (1) to (3) indicate a very large burden of care.

Other Points: The assessment of walking does not usually include the subcomponent of standing up initially from a seated position. This is more accurately assessed under transfers.

The main issue of debate lies in the distance that needs to be covered to be considered significant. Most authorities divide threshold distances into household ambulation and community ambulation. Household ambulation is the distance required generally to move within the home environment and would plausibly cover the distance between a room and a toilet. This is taken as 50 feet (17 meters) in the FIM instrument¹⁶⁻⁷. However, the FIM was based on home sizes in the United States which are probably larger. The average 3-room HDB flat (2 bedrooms, 1 kitchen/ dining room and a living room) measures about 64

square meters²¹. A reasonable distance for significant household ambulation would then be eight meters.

Community ambulation is the distance required to move for IADL purposes such as grocery shopping or to the nearest bus-stop. This is generally taken as one 'block' in Western societies and measures 50 meters in the modified BI and FIM¹⁴⁻⁷. Fifty meters also seems a reasonable distance in the local context: this is the minimum distance between a pedestrian crossing (for example, traffic lights, overhead bridge or zebra crossing) and a point where we can cross the road without using the pedestrian crossing. However, we use a household ambulation of eight meters as our threshold significant distance because we feel that a large majority of disabled patients are house-bound in Singapore and this more accurately reflects burden of care.

Some patients with significant paralysis of all limbs including patients with high cervical spinal cord injury or multiple sclerosis use a powered or electric wheelchair for mobility. The threshold distances do not change because again, we are measuring the amount of assistance required and not the patient's ability to propel a wheelchair primarily.

REHABILITATION AND ACTIVITIES OF DAILY LIVING

Rehabilitation improves functional outcomes including the performance of ADLs^{4,10}. This improvement in function can occur even after the recovery of the primary disease process is complete. The principles of improving functional capacity in rehabilitation include direct retraining, compensatory processes, and environmental modifications. Recent advances in rehabilitation include more efficient retraining strategies and the realisation that rehabilitation is most effective when a functional approach is employed. The readers are directed elsewhere in this issue for further details on rehabilitation and disability as well as rehabilitation resources available.

EXPERIENCES, STRENGTHS, WEAKNESSES AND CONCLUSIONS

We have published local data on more than 1,500 patients with various diseases in which we have performed disability assessments on during their rehabilitation course⁴. Our experience is that clinicians often overestimate the capabilities of the patients and consequently underestimate the amount of assistance required, and this has been a common experience in many rehabilitation centers¹³. Some care in assessing disability using the guidelines above will overcome this issue. There are also concerns with regards to false self-reporting of disability among claimants, but because of the high prevalence of disability locally, particularly with evidence of a chronic disease such as stroke or diabetes, it is necessary to apply some common sense for patient beneficence^{3,22}.

All scales or instruments whereby disabilities are measured are subject to several weaknesses, and the assessor in scoring

and interpretation should take these into account during test administration. Major weaknesses include:

1. Disability scales are by nature quantitative and ordinal. Categories of disability severity are not equal. For example, on a scale of 1 (most severe) to 10 (least severe), 2 may not be twice as severe as 1, or 3 twice as severe as 2.
2. There is subjectivity in how each disability item should be measured. What constitutes a certain quantum of assistance cannot be perfectly objectively defined. As such, there is continual refinement in the disability assessment literature itself and the focus currently is on refinement of existing scales rather than developing new ones¹³.
3. Content validity. There is no agreement which and how many items need to be included in any disability instrument to provide the optimal representation of disability.
4. Inter-rater reliability. Clinicians who administer disability testing on a regular basis will have better inter-rater reliability versus those who perform testing only occasionally or rarely.

CONCLUSION

Accurate disability assessment of the basic activities of daily living is important as a clinical, research, education and epidemiologic tool. It also functions as a social policy tool for health-care funding, directing rehabilitation resources, as well fulfills an important role in advocating for the disabled in Singapore. Disability assessment requires review over time to maintain relevancy, and long-term goals could be the development and maintenance of a disability database in Singapore.

DISCLAIMER

In this article, we provide a general overview of disability assessment and a possible schema of assessment based on published literature and our experiences in this field. The text will not be applicable to all schemes and policies and the views and opinions expressed are of the authors only.

The ADL definitions and the method in which the severity of disability is categorised vary considerably between the disability-related national schemes and third-party insurers. Similarly, the thresholds and disability category whereby the claimant is successful in obtaining claims also vary significantly between the disability-related national schemes and insurers. The authors will not be held responsible for any disputes that arise in the claims process and the assessor is advised to check with the particular scheme and insurer for details and updates on the assessment process regularly. The authors are currently not affiliated to any disability-related national scheme or third party insurer.

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LEARNING POINTS

- **The assessment of disability including activities of daily living is important as a clinical tool.**
- **A practical framework of an independent category and four dependent categories corresponding to an increasing level of assistance for each ADL is used in assessment of ability to perform activities of daily living in adults.**
- **Clinicians who administer disability testing on a regular basis will have better inter-rater reliability versus those who perform testing only occasionally or rarely.**
- **Rehabilitation improves functional outcomes including the performance of ADLs.**

ASSESSMENT OF 30 MCQs

FPSC NO : 49
MCQs on UPDATE ON FUNCTION AND DISABILITY IN
PRIMARY CARE
Submission DEADLINE : 7 JULY 2012

INSTRUCTIONS

- To submit answers to the following multiple choice questions, you are required to log on to the College On-line Portal (www.cfps2online.org).
- Attempt ALL the following multiple choice questions.
- There is only ONE correct answer for each question.
- The answers should be submitted to the College of Family Physicians Singapore via the College On-line Portal before the submission deadline stated above.

1. About common physical disabilities in childhood, which of the following is NOT progressive?
 - A. Spinal muscular atrophy (SMA).
 - B. Spinal bifida cystica.
 - C. Cerebral palsy.
 - D. Spinal dysraphism.
 - E. Duchenne muscular dystrophy (DMD).
2. Duchenne muscular dystrophy (DMD) affects 1 per X male births. What is X?
 - A. 2,000.
 - B. 2,500.
 - C. 3,000.
 - D. 3,500.
 - E. 4,000.
3. About the prevention of spina bifida, a Medical Research Council Vitamin Study Group in a multi-centre randomized control trial showed that maternal peri-conceptional folic acid supplementation provided a X% protective effect. What is X?
 - A. 64.
 - B. 66.
 - C. 68.
 - D. 70.
 - E. 72.
4. After Down's syndrome, which of the following is the most common cause for mental retardation in boys?
 - A. Prader-Willie syndrome.
 - B. Tuberous sclerosis.
 - C. Fragile X syndrome.
 - D. Duchenne muscular dystrophy.
 - E. Spinal muscular atrophy.
5. A 2-year-old child is brought by his mother to see you because he was noted to have difficulty communicating, loves repeatedly opening and closing doors, and gets upset if his toys are disarranged by his brother. Which of the following is the most likely diagnosis?
 - A. Attention deficit hyperactive disorder.
 - B. Autistic spectrum disorder.
 - C. Asperger syndrome.
 - D. Obsessive compulsive disorder.
 - E. Fragile X syndrome.
6. A 4-year-old boy is brought to see you because for the last 6 months, he seems to have difficulty climbing up and down the stairs. The diagnosis is supported by a creatinine kinase which is raised in up to X% of such patients. What is X?
 - A. 72.
 - B. 62.
 - C. 52.
 - D. 42.
 - E. 32.
7. About the ability of children to dress themselves, most X-year-olds are able to undress and dress independently. What is X?
 - A. 2.
 - B. 3.
 - C. 4.
 - D. 5.
 - E. 6.
8. About the ability of children to feed themselves, by the age of X, they are able to eat skillfully with a fork and spoon. What is X?
 - A. 2.
 - B. 3.
 - C. 4.
 - D. 5.
 - E. 6.

9. **Encopresis is defined as regular soiling of the underwear in children aged X years and older, with no organic disease. What is X?**
- 2.
 - 3.
 - 4.
 - 5.
 - 6.
10. **About transferring and mobility in children, by the age of X, they are able to walk or run alone up and down stairs, one foot to a step in adult fashion. What is X?**
- 2.
 - 3.
 - 4.
 - 5.
 - 6.
11. **About bathing, typically children in Singapore start bathing independently from the age of X. What is X?**
- 2 or 3.
 - 3 or 4.
 - 4 or 5.
 - 5 or 6.
 - 6 or 7.
12. **Developmental disabilities are a group of chronic disorders of early onset estimated to affect X% of children. What is X?**
- 5 to 10.
 - 10 to 15.
 - 15 to 20.
 - 20 to 25.
 - 25 to 30.
13. **About the prevalence of disability of women at all ages compared to men, which of the following is most likely answer?**
- The prevalence of disability in women is lower than men at all ages in rural communities.
 - Women tend to have a higher prevalence than men at all ages.
 - The prevalence of disability in women is higher than men at all ages in urban communities.
 - Women tend to have a lower prevalence than men at all ages.
 - The difference in prevalence is unknown.
14. **In a community study done in Singapore to assess the functional status of those 60 years and older, X% were dependent in at least one area of ADL. What is X?**
- 21.
 - 20.
 - 19.
 - 18.
 - 17.
15. **A person with 3 impairments has a X% likelihood of developing disability in the next one year. What is X?**
- 30.
 - 40.
 - 50.
 - 60.
 - 70.
16. **A 65-year-old woman complains of pain and stiffness of both shoulders and the neck. She is diagnosed to have polymyalgia rheumatica. Which of the following is a complication that may occur?**
- High tone hearing loss.
 - Blindness.
 - Unsteady gait.
 - Anxiety symptoms.
 - Dry mouth.
17. **Older persons decondition rapidly when they lie in bed. For every 24 hours of bed rest, the person loses X% of muscle tone and this is translated clinically into weaker muscles. What is X?**
- 3.
 - 5.
 - 8.
 - 10.
 - 20.
18. **A 70-year-old person complains of hearing loss of a week's duration. Which of the following is the most common cause?**
- Impacted ear wax.
 - Noise induced hearing loss.
 - Otitis media.
 - Perforated tympanic membrane.
 - Meniere's disease.
19. **In the United States, a 2008 survey amongst people in the civilian non-institutionalised population aged 5 years and older, showed that X% reported ambulatory difficulty (walking or climbing stairs). What is X?**
- 4.9.
 - 5.9.
 - 6.9.
 - 7.9.
 - 8.9.
20. **In a World Health Survey, it was noted that X% of people aged 15 and older lived with disability. What is X?**
- 11.6.
 - 12.6.
 - 13.6.
 - 14.6.
 - 15.6.

21. About the therapeutic effects of various modalities of physiotherapy, which of the following pair of association of mode of therapy and therapeutic effects is CORRECT?

- A. Heat therapy – decreases activity of enzymes that may damage the joint.
- B. Cold therapy – improved blood flow and increased non-elastic tissue extensibility.
- C. Hydrotherapy – improves circulation and reduces edema.
- D. Iontophoresis – improves circulation with pumping action.
- E. Electrical stimulation – produces positive psychological benefits.

22. About the therapeutic effect of various medications used in rehabilitation, which of the following pair of association of symptom or sign and medication is CORRECT?

- A. Spasticity – Baclofen, Carisprodol
- B. Autonomic dysreflexia – Amitriptyline, Capsaicin.
- C. Neuropathic pain – Nifedipine, Hydralazine.
- D. Bladder management – Methyphenidate, Haloperidol
- E. Psycho-modulation – Oxybutinin, Flavoxate.

23. About the type of exercise and description or example, which of the following pair of association of exercise and description or example is CORRECT?

- A. Isokinetic – constant velocity or accommodating resistance exercise.
- B. Open kinetic chain – squats or running.
- C. Closed kinetic chain – leg press or cycling.
- D. Power building exercise – high repetition, low resistance exercise.
- E. Endurance building exercise – low repetition, high resistance exercise.

24. About the initial assessment for in-patient rehabilitation, which of the following is the LEAST important item?

- A. Neurological and musculoskeletal deficits.
- B. Financial status.
- C. Medical co-morbidities.
- D. Cognitive deficits.
- E. Family dynamics.

25. Singapore shares a common trend with most developed countries whereby non-communicable diseases account for X% of the principal causes of death. What is X?

- A. 60.
- B. 65.
- C. 70.
- D. 75.
- E. 80.

26. About IADL (Instrumental activity of daily living) which of the following is an example?

- A. Grooming.
- B. Toileting.
- C. Wheelchair use.
- D. Medication use.
- E. Climbing stairs.

27. A patient presents for Eldersfield assessment. He has a stroke requiring only minimal assistance with dressing of the upper body, such as wearing a shirt, but requires moderate assistance in dressing of the lower body, such as the wearing of trousers. What should the score be for dressing?

- A. Independence.
- B. Minimal assistance required.
- C. Moderate assistance required.
- D. Maximal assistance required.
- E. Total assistance required.

28. A patient with advanced rheumatoid arthritis presents for Eldersfield assessment. He requires maximal assistance in the morning in eating because of early morning stiffness and fatigue, but subsequently performs better in the evening. What should the score be for feeding?

- A. Independence.
- B. Minimal assistance required.
- C. Moderate assistance required.
- D. Maximal assistance required.
- E. Total assistance required.

29. A patient presents for Eldersfield assessment. He has a stroke requiring only minimal assistance to move from bed to chair, but requires moderate assistance to move from chair to bed. What should the score be for mobility?

- A. Independence.
- B. Minimal assistance required.
- C. Moderate assistance required.
- D. Maximal assistance required.
- E. Total assistance required.

30. A patient presents for Eldersfield assessment. He has a spinal cord injury with complete paraplegia. He is able to propel a wheelchair more than 50 meters in a straight well paved corridor. He lives in a one room flat which makes it difficult to move his wheelchair around and maximal assistance is needed. What should the score be for mobility?

- A. Independence.
- B. Minimal assistance required.
- C. Moderate assistance required.
- D. Maximal assistance required.
- E. Total assistance required.

Forging Greater Inclusiveness and Enablement in the Singapore Disability Landscape



An Overview

The first Enabling Masterplan 2007-2011 lays the foundation for the **creation of an inclusive society in Singapore** to support those who are disadvantaged and help them to reach their full potential. It charts the development of programmes and services in the disability sector focusing on the integration of persons with disabilities (PWDs) and to maximise their potential for independent living.

The Enabling Masterplan 2012-2016 expands on the foundation laid by the earlier Masterplan to propel Singapore towards an inclusive society. To better meet the needs of PWDs and their caregivers, **the new Masterplan adopts a life-course approach starting with the early pre-school years, then to the education and employment phase of life, and the adult and ageing years.**

The two central themes running through the Enabling Masterplan are that of **inclusiveness** and **enablement**.

Key Recommendations of the Enabling Masterplan 2012-2016

The recommendations of the Masterplan have been guided by the following principles to:

- Take an inclusive approach towards PWDs;
- Recognise the autonomy and independence of PWDs;
- Take an integrated approach with the support of the 3P – People, Private and Public; and
- Involve the community as a source of support and empower families to care.

A. For Early Intervention

- Establish a network of early detection touch points and developmental screening program for children at various stages from as early as 9 to 30 months
- Enhance the accessibility to more early intervention and family-support services by developing clusters of private and public agencies to support children with developmental needs and studying the feasibility of an early childhood stimulation program
- Equip caregivers with resources, information, early intervention skills and knowledge

B. For Education

- Develop a pre-service training incorporating general education, special education and disability specialty
- Customise curriculum and pedagogy for school-specific teaching and learning initiatives for special education schools
- Develop a structured caregiving engagement program which equips family caregivers to better support the learning of students with special needs

C. For Adults with Disabilities

- Develop group homes in the community for PWDs who have low or no family support but are able to live independently with support
- Introduce home-based care services for PWDs
- Widen and deepen the use of technology to enhance quality of services and safety in adult disability services

D. For Caregiver Support and Transition Management

- Develop more respite care options to give caregivers short term and temporary relief
- Establish dedicated child care and student care services
- Increase psycho-emotional support services

E. For Capability Building

- Optimise the use of assistive technology (AT), information and communication technology (ICT), and education technology in special education schools to enhance teaching and learning and assistance in daily living activities
- Provide consultancy support and knowledge transfer on AT and ICT to voluntary welfare organisations so as to benefit PWDs
- Engage relevant industry clusters to implement accessible technologies and best practices for inclusion

F. For Community Integration and Accessibility

- Study and research on international best practices to understand the transport needs of PWDs and improve transport accessibility and universality
- Develop dedicated transport providers for accessible vehicles to cater to the specific needs of the elderly and PWDs
- Improve access to information and communication with PWDs

G. For Sports and Healthy Lifestyle

- Incorporate nutrition, mental health, sports and games, and sexuality education into the curriculum of special education schools
- Provide more opportunities for participation in sports and games
- Create a range of sports opportunities that are accessible and inclusive to PWDs

For the full report of the Enabling Masterplan 2012-2016, please go to the following link,
<http://app1.mcys.gov.sg/Policies/DisabilitiesPeoplewithDisabilities/EnablingMasterplan20122016.aspx>



R E A D I N G S

- A Selection of Ten Current Readings on Topics Related to Function & Disability in Primary Care

A SELECTION OF TEN CURRENT READINGS ON TOPICS RELATED TO FUNCTION & DISABILITY IN PRIMARY CARE –

Some available as free full-text and some requiring payment

Selection of readings made by A/Prof Goh Lee Gan

READING 1 – GLOBAL BURDEN OF DISEASE IN YOUNG PEOPLE

Gore FM, Bloem PJ, Patton GC, Ferguson J, Joseph V, Coffey C, Sawyer SM, Mathers CD. Global burden of disease in young people aged 10-24 years: a systematic analysis. Lancet. 2011 Jun 18;377(9783):2093-102. Epub 2011 Jun 7.

URL: <http://www.sciencedirect.com/science/article/pii/S0140673611605126> (payment required)

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Erratum in Lancet. 2011 Aug 6;378(9790):486.

Comment in

Lancet. 2012 Jan 7;379(9810):27-8; author reply 28.

Lancet. 2011 Jun 18;377(9783):2058-60.

Lancet. 2011 Jun 18;377(9783):2056.

Lancet. 2012 Jan 7;379(9810):29.

ABSTRACT

BACKGROUND: Young people aged 10-24 years represent 27% of the world's population. Although important health problems and risk factors for disease in later life emerge in these years, the contribution to the global burden of disease is unknown. We describe the global burden of disease arising in young people and the contribution of risk factors to that burden.

METHODS: We used data from WHO's 2004 Global Burden of Disease study.

Cause-specific disability-adjusted life-years (DALYs) for young people aged 10-24 years were estimated by WHO region on the basis of available data for incidence, prevalence, severity, and mortality. WHO member states were classified into low-income, middle-income, and high-income countries, and into WHO regions. We estimated DALYs attributable to specific global health risk factors using the comparative risk assessment method. DALYs were divided into years of life lost because of premature mortality (YLLs) and years lost because of disability (YLDs), and are presented for regions by sex and by 5-year age groups.

FINDINGS: The total number of incident DALYs in those aged 10-24 years was about 236 million, representing 15.5% of total DALYs for all age groups. Africa had the highest rate of DALYs for this age group, which was 2.5 times greater than in high-income countries (208 vs 82 DALYs per 1000 population). Across regions, DALY rates were 12% higher in girls than in boys between 15 and 19 years (137 vs 153). Worldwide, the three main causes of YLDs for 10-24-year-olds were neuropsychiatric disorders (45%), unintentional injuries (12%), and infectious and parasitic diseases (10%). The main risk factors for incident DALYs in 10-24-year-olds were alcohol (7% of DALYs), unsafe sex (4%), iron deficiency (3%), lack of contraception (2%), and illicit drug use (2%).

INTERPRETATION: The health of young people has been largely neglected in global public health because this age group is perceived as healthy. However, opportunities for prevention of disease and injury in this age group are not fully exploited. The findings from this study suggest that adolescent health would benefit from increased public health attention.

FUNDING: None.

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READING 2 – CEREBRAL PALSY IN CHILDHOOD

Reddihough D. Cerebral palsy in childhood. Aust Fam Physician. 2011 Apr;40(4):192-6.

URL: <http://www.racgp.org.au/afp/201104/42236> (free full text)

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ABSTRACT

BACKGROUND: Cerebral palsy is the most common cause of physical disability in childhood. While some children have only a motor disorder, others have a range of problems and associated health issues.

OBJECTIVE: This article describes the known causes of cerebral palsy, the classification of motor disorders and associated disabilities, health maintenance, and the consequences of the motor disorder. The importance of multidisciplinary assessment and treatment in enabling children to achieve their optimal potential and independence is highlighted.

DISCUSSION: General practitioners play an important role in the management of children with cerebral palsy. Disability is a life-long problem which impacts on the child, their parents and their siblings. After transition to adult services, the GP may be the only health professional that has known the young person over an extended period, providing important continuity of care.

PMID: 21597527 [PubMed - indexed for MEDLINE]

READING 3 – LIFESTYLE CHANGE AND MOBILITY IN OBESE ADULTS WITH DIABETES

Rejeski WJ, Ip EH, Bertoni AG, Bray GA, Evans G, Gregg EW, Zhang Q; Look AHEAD Research Group. Lifestyle change and mobility in obese adults with type 2 diabetes. N Engl J Med. 2012 Mar 29;366(13):1209-17.

URL: <http://www.nejm.org/doi/full/10.1056/NEJMoa1110294> (payment required)

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ABSTRACT

BACKGROUND: Adults with type 2 diabetes mellitus often have limitations in mobility that increase with age. An intensive lifestyle intervention that produces weight loss and improves fitness could slow the loss of mobility in such patients.

METHODS: We randomly assigned 5145 overweight or obese adults between the ages of 45 and 74 years with type 2 diabetes to either an intensive lifestyle intervention or a diabetes support-and-education program; 5016 participants contributed data. We used hidden Markov models to characterize disability states and mixed-effects ordinal logistic regression to estimate the probability of functional decline. The primary outcome was self-reported limitation in mobility, with annual assessments for 4 years.

RESULTS: At year 4, among 2514 adults in the lifestyle-intervention group, 517 (20.6%) had severe disability and 969 (38.5%) had good mobility; the numbers among 2502 participants in the support group were 656 (26.2%) and 798 (31.9%), respectively. The lifestyle-intervention group had a relative reduction of 48% in the risk of loss of mobility, as compared with the support group (odds ratio, 0.52; 95% confidence interval, 0.44 to 0.63; $P < 0.001$). Both weight loss and improved fitness (as assessed on treadmill testing) were significant mediators of this effect ($P < 0.001$ for both variables). Adverse events that were related to the lifestyle intervention included a slightly higher frequency of musculoskeletal symptoms at year 1.

CONCLUSIONS: Weight loss and improved fitness slowed the decline in mobility in overweight adults with type 2 diabetes. (Funded by the Department of Health and Human Services and others; ClinicalTrials.gov number, NCT00017953.).

PMCID: PMC3339039 [Available on 2012/9/29] PMID: 22455415 [PubMed - indexed for MEDLINE]

READING 4 – INTEGRATIVE CARE IN REDUCING DISABILITY

Von Korff M, Katon WJ, Lin EH, Ciechanowski P, Peterson D, Ludman EJ, Young B, Rutter CM. Functional outcomes of multi-condition collaborative care and successful ageing: results of randomised trial. BMJ. 2011 Nov 10;343:d6612. doi: 10.1136/bmj.d6612.

URL: <http://www.bmj.com/content/343/bmj.d6612?view=long&pmid=22074851> (free full text)

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ABSTRACT

OBJECTIVE: To evaluate the effectiveness of integrated care for chronic physical diseases and depression in reducing disability and improving quality of life.

DESIGN: A randomised controlled trial of multi-condition collaborative care for depression and poorly controlled diabetes and/or risk factors for coronary heart disease compared with usual care among middle aged and elderly people.

SETTING: Fourteen primary care clinics in Seattle, Washington.

PARTICIPANTS: Patients with diabetes or coronary heart disease, or both, and blood pressure above 140/90 mm Hg, low density lipoprotein concentration >3.37 mmol/L, or glycated haemoglobin 8.5% or higher, and PHQ-9 depression scores of ≥ 10 .

INTERVENTION: A 12 month intervention to improve depression, glycaemic control, blood pressure, and lipid control by integrating a “treat to target” programme for diabetes and risk factors for coronary heart disease with collaborative care for depression. The intervention combined self management support, monitoring of disease control, and pharmacotherapy to control depression, hyperglycaemia, hypertension, and hyperlipidaemia.

MAIN OUTCOME MEASURES: Social role disability (Sheehan disability scale), global quality of life rating, and World Health Organization disability assessment schedule (WHODAS-2) scales to measure disabilities in activities of daily living (mobility, self care, household maintenance).

RESULTS: Of 214 patients enrolled (106 intervention and 108 usual care), disability and quality of life measures were obtained for 97 intervention patients at six months (92%) and 92 at 12 months (87%), and for 96 usual care patients at six months (89%) and 92 at 12 months (85%). Improvements from baseline on the Sheehan disability scale (-0.9, 95% confidence interval -1.5 to -0.2; $P = 0.006$) and global quality of life rating (0.7, 0.2 to 1.2; $P = 0.005$) were significantly greater at six and 12 months in patients in the intervention group. There was a trend toward greater improvement in disabilities in activities of daily living (-1.5, -3.3 to 0.4; $P = 0.10$).

CONCLUSIONS: Integrated care that covers chronic physical disease and comorbid depression can reduce social role disability and enhance global quality of life.

Trial registration Clinical Trials NCT00468676. PMCID: PMC3213240 PMID: 22074851 [PubMed - indexed for MEDLINE]

READING 5 – INTERVENTIONS INCLUDING EXERCISE MAY IMPROVE PARTICIPATION IN LIFE ROLES IN OLDER PEOPLE

Fairhall N, Sherrington C, Clemson L, Cameron ID. Do exercise interventions designed to prevent falls affect participation in life roles? A systematic review and meta-analysis. Age Ageing. 2011 Nov;40(6):666-74. Epub 2011 Jul 14.

URL: <http://ageing.oxfordjournals.org/content/40/6/666.long> (payment required)

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ABSTRACT

BACKGROUND: the World Health Organization describes individuals' functioning at a societal level as 'participation'. Despite being a key component of functioning and an important goal of rehabilitation, participation is not measured

consistently in ageing research. The aim was to evaluate the extent to which measurement of participation has been reported in trials of fall prevention interventions and to determine the effect of exercise interventions on participation in life roles.

METHODS: systematic review with meta-analysis. Randomised controlled trials of exercise interventions that aimed to reduce falls in older people (60+) in community, aged care facilities or hospital settings were included. The outcome of interest was participation in life roles. Trials that measured participation at two time-points were included in the meta-analysis.

RESULTS: ninety-six trials met the review inclusion criteria. Participation was measured in 19 of these trials (20%). Nine instruments were used to measure participation. Fifteen trials, involving 3,616 participants, were included in the meta-analysis. The pooled estimate of the effect of interventions including exercise indicated a small improvement in participation (Hedges' $g = 0.16$, 95% confidence interval = 0.04-0.27, $P = 0.006$). Meta-regression showed multifactorial intervention with an exercise component had a larger effect than exercise intervention alone, but the difference was not statistically significant (effect on Hedges' $g = 0.22$, 95% CI = -0.05 to 0.50, $P = 0.10$). **CONCLUSION:** interventions including exercise may improve participation in life roles in older people. The International Classification of Functioning, Disability and Health may be a useful framework for understanding the broader impact of falls prevention interventions.

SYSTEMATIC REVIEW REGISTRATION: ACTRN12610000862044. PMID: 21764816 [PubMed - indexed for MEDLINE]

READING 6 – DISABILITY PREVENTION PROGRAMME FOR COMMUNITY-DWELLING FRAIL OLDER PERSONS

Daniels R, van Rossum E, Metzelthin S, Sipers W, Habets H, Hobma S, van den Heuvel W, de Witte L. A disability prevention programme for community-dwelling frail older persons. Clin Rehabil. 2011 Nov;25(11):963-74. Epub 2011 Aug 17.

URL: <http://cre.sagepub.com/pmidlookup?view=long&pmid=21849375> (free full text)

Faculty of Health and Care, Zuyd University of Applied Sciences, Heerlen, The Netherlands. r.daniels@hszuyd.nl

ABSTRACT

OBJECTIVE: To describe and justify a primary care interdisciplinary programme for community-dwelling frail older people aimed to prevent disability. **BACKGROUND:** Disability is a negative outcome of frailty among older persons. Policy reports and research studies emphasize the need for programmes to reduce disability progression. Between 2008 and 2010 we developed such a programme.

DEVELOPMENT: Following the Intervention Mapping protocol, a research team and a multidisciplinary professional developed the programme. Literature reviews and an expert meeting led to identification of basic elements, theory-based methods and practical tools.

THE PROGRAMME: The general practitioner and the practice nurse comprise the core team that can be extended by other professionals such as occupational and physical therapist. The programme includes six steps: (1) screening, (2) assessment, (3) analysis and preliminary action plan, (4) agreement on an action plan, (5) execution of the action plan (toolbox parts) and (6) evaluation and follow-up. The main features are: identifying risks for developing disability and targeting risk factors using professional standards and the 5A Behavioural Change Model to support self management, and identifying problems in performing activities and enhancing meaningful activities based on the Model of Human Occupation. Screening, individual assessment, tailor-made and client-centred care, self-management support, case management and interdisciplinary cooperation are important principles in delivering the programme.

DISCUSSION: The disability-prevention programme seems promising for addressing the needs of frail older people for independent living and for targeting risk factors. Its feasibility and effects are currently being tested in a randomized controlled trial.

PMID: 21849375 [PubMed - indexed for MEDLINE]

READING 7 – RESISTANCE EXERCISE FOR THE AGING ADULT

Peterson MD, Gordon PM. Resistance exercise for the aging adult: clinical implications and prescription guidelines. Am J Med. 2011 Mar;124(3):194-8.

URL: <http://www.sciencedirect.com/science/article/pii/S0002934310009277> (payment required)

Laboratory for Physical Activity and Exercise Intervention Research, Department of Physical Medicine and Rehabilitation, University of Michigan, Ann Arbor, 48108-46202, USA.

ABSTRACT

Sarcopenia and weakness are known to precipitate risk for disability, comorbidity, and diminished independence among aging adults. Resistance exercise has been proposed as a viable intervention to elicit muscular adaptation and improve function. However, the reported prevalence of resistance exercise participation among US adults aged >50 years is very low. This may be largely attributable to inconsistency in study results that fail to fully inform the clinical and public health community of its overall value. Therefore, the purpose of this commentary review is to report the findings of recently published meta-analyses that systematically examined the overall value of resistance exercise among healthy aging adults for strength and lean body mass outcomes. Evidence reveals that not only is resistance exercise very effective for eliciting strength gain and increases in lean body mass, but that there is a dose-response relationship such that volume and intensity are strongly associated with adaptations. These findings reflect and support the viability of progression in resistance exercise dosage to accommodate optimal muscular adaptive response. Progressive resistance exercise should thus be encouraged among healthy adults to minimize degenerative muscular function associated with aging.

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PMID: 21396499 [PubMed - indexed for MEDLINE]

READING 8 – REHABILITATION REDUCES ACUTE EXACERBATIONS IN CHRONIC OBSTRUCTIVE PULMONARY DISEASE

Burtin C, Decramer M, Gosselink R, Janssens W, Troosters T. Rehabilitation and acute exacerbations. Eur Respir J. 2011 Sep;38(3):702-12. Epub 2011 Jun 30.

URL: <http://erj.ersjournals.com/cgi/pmidlookup?view=long&pmid=21719481> (payment required)

University Hospitals KU Leuven, Respiratory Rehabilitation and Respiratory Division, Leuven, Belgium.

ABSTRACT

Recent evidence indicates that acute exacerbations of chronic obstructive pulmonary disease aggravate the extrapulmonary consequences of the disease. Skeletal muscle dysfunction, a sustained decrease in exercise tolerance, enhanced symptoms of depression and fatigue are reported. Avoidance of physical activities is likely to be a key underlying mechanism and increases the risk of new exacerbations. Pulmonary rehabilitation is an intervention targeting these systemic consequences. Exercise strategies need to be adapted to the increased feelings of dyspnoea and fatigue. This review aims to describe the systemic consequences of acute exacerbations and compiles evidence for the feasibility and effectiveness of different rehabilitation strategies to counteract these consequences during and/or immediately after the acute phase of the exacerbation.

Resistance training and neuromuscular electrical stimulation have been applied safely in frail, hospitalised patients and have the potential to prevent muscle atrophy. Comprehensive pulmonary rehabilitation, including general exercise training, can be implemented immediately after the exacerbation, leading to a reduction in hospital admissions and an increase in exercise tolerance and quality of life. Self-management strategies play a crucial role in changing disease-related health behaviour and preventing hospital admissions.

PMID: 21719481 [PubMed - indexed for MEDLINE]

READING 9 – PREVENTING READMISSIONS AND LOSS OF FUNCTIONAL ABILITY

Courtney MD, Edwards HE, Chang AM, Parker AW, Finlayson K, Hamilton K. A randomised controlled trial to prevent hospital readmissions and loss of functional ability in high risk older adults: a study protocol. BMC Health Serv Res. 2011 Aug 23;11:202.

URL: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3224378/?tool=pubmed> (free full text)

Faculty of Health and Social Development, University of British Columbia, Okanagan, Canada.

ABSTRACT

BACKGROUND: Older people have higher rates of hospital admission than the general population and higher rates of readmission due to complications and falls. During hospitalisation, older people experience significant functional decline which impairs their future independence and quality of life. Acute hospital services comprise the largest section of health expenditure in Australia and prevention or delay of disease is known to produce more effective use of services. Current models of discharge planning and follow-up care, however, do not address the need to prevent deconditioning or functional decline. This paper describes the protocol of a randomised controlled trial which aims to evaluate innovative transitional care strategies to reduce unplanned readmissions and improve functional status, independence, and psycho-social well-being of community-based older people at risk of readmission.

METHODS/DESIGN: The study is a randomised controlled trial. Within 72 hours of hospital admission, a sample of older adults fitting the inclusion/exclusion criteria (aged 65 years and over, admitted with a medical diagnosis, able to walk independently for 3 meters, and at least one risk factor for readmission) are randomised into one of four groups: 1) the usual care control group, 2) the exercise and in-home/telephone follow-up intervention group, 3) the exercise only intervention group, or 4) the in-home/telephone follow-up only intervention group. The usual care control group receive usual discharge planning provided by the health service. In addition to usual care, the exercise and in-home/telephone follow-up intervention group receive an intervention consisting of a tailored exercise program, in-home visit and 24 week telephone follow-up by a gerontic nurse. The exercise only and in-home/telephone follow-up only intervention groups, in addition to usual care receive only the exercise or gerontic nurse components of the intervention respectively. Data collection is undertaken at baseline within 72 hours of hospital admission, 4 weeks following hospital discharge, 12 weeks following hospital discharge, and 24 weeks following hospital discharge. Outcome assessors are blinded to group allocation. Primary outcomes are emergency hospital readmissions and health service use, functional status, psychosocial well-being and cost effectiveness.

DISCUSSION: The acute hospital sector comprises the largest component of health care system expenditure in developed countries, and older adults are the most frequent consumers. There are few trials to demonstrate effective models of transitional care to prevent emergency readmissions, loss of functional ability and independence in this population following an acute hospital admission. This study aims to address that gap and provide information for future health service planning which meets client needs and lowers the use of acute care services.

TRIAL REGISTRATION NO: Australian & New Zealand Clinical Trials Registry ACTRN12608000202369.
PMCID: PMC3224378 **PMID:** 21861920 [PubMed - indexed for MEDLINE]

READING 10 – REDUCING HOSPITALISATION-ASSOCIATED DISABILITY

Covinsky KE, Pierluissi E, Johnston CB. Hospitalization-associated disability: “She was probably able to ambulate, but I’m not sure”. JAMA. 2011 Oct 26;306(16):1782-93.

URL: <http://jama.jamanetwork.com/article.aspx?doi=10.1001/jama.2011.1556> (payment required)

Department of Medicine and Division of Geriatrics, University of California, San Francisco, San Francisco, CA 94121, USA. ken.covinsky@ucsf.edu

ABSTRACT

In older patients, acute medical illness that requires hospitalization is a sentinel event that often precipitates disability. This results in the subsequent inability to live independently and complete basic activities of daily living (ADLs). This hospitalization-associated disability occurs in approximately one-third of patients older than 70 years of age and may be triggered even when the illness that necessitated the hospitalization is successfully treated. In this article, we describe risk factors and risk stratification tools that identify older adults at highest risk of hospitalization-associated disability. We describe hospital processes that may promote hospitalization-associated disability and models of care that have been developed to prevent it. Since recognition of functional status problems is an essential prerequisite to preventing and managing disability, we also describe a pragmatic approach toward functional status assessment in the hospital focused on evaluation of ADLs, mobility, and cognition. Based on studies of acute geriatric units, we describe interventions hospitals and clinicians can consider to prevent hospitalization-associated disability in patients. Finally, we describe approaches clinicians can implement to improve the quality of life of older adults who develop hospitalization-associated disability and that of their caregivers.

PMID: 22028354 [PubMed - indexed for MEDLINE]



Am I a caregiver?

What does caregiving entail?

Where should I go to if I needed help myself?

If you are looking after an elderly, disabled or a chronically or mentally ill person and had asked yourself these questions before, you are a caregiver.

A lot of times, people providing care to others do not even know that they are caregivers. They think that it is part and parcel of their “duty” to care for their loved ones.

Caregiving is not just about taking care of the physical but also emotional and psychological needs of the person you are caring for. It is indeed a challenging task.

The Centre for Enabled Living (CEL) and Agency for Integrated Care (AIC) have collaborated to produce a caregivers’ guide, entitled **Caregiver Basics 101 – A Resource Guide for New Caregivers.**

It is a simple but informative guide with beautiful illustrations and easy-to-follow tips. The guide is divided into several sections including training to enhance caregiving skills, financial and legal advices, tips on home safety and resources listing the various service providers for home help, respite care and caregiver support, etc.

If you would like to request for a copy of the resource guide, please contact CEL at 1800-8585 885. Alternatively, you may access it on-line at http://www.cel.sg/Resources_Useful_Links_Publications.aspx.

GUIDELINES AND INFORMATION FOR AUTHORS

THE SINGAPORE FAMILY PHYSICIAN

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The following types of articles may be suitable for publication: case reports/study, original research works, audits of patient care, protocols for patient or practice management and letters to the Editor. The CME and review articles will be published under the prerogative of the Institute of Family Medicine (IFM) in the College of Family Physicians Singapore. The article should be written in British English, and not be more than 3000 words in length. This must be submitted in an electronic form and of a format that is compatible with major word processor applications. Submissions in Microsoft Word in Word 1997-2003 format (.doc) is preferred, later versions (.docx) will not be accepted.

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 3. Key Words
 4. Text/ Manuscript (anonymised version)
 5. Tables
 6. Illustrations
 7. Authors Agreement/ Copyright Assignment Form
 8. Patient's Consent Form, if necessary (including consent for photograph or illustration taken of human subject)
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- Include name, address, handphone number and email address of the first author to whom correspondence should be sent.
- Insert at the bottom: name and address of institution or practice from which the work originated.

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Key Words

- Add, at the end of summary in alphabetical listing, keywords of up to 5 in number which will be used for article indexing and retrieval under Medical Subject Headings or MeSH. MeSH is the NLM controlled vocabulary thesaurus used for indexing articles for WPRIM and PubMed. Please refer to www.nlm.nih.gov/mesh/ for details.

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The text should have the following sequence:

- **Introduction:** State clearly the purpose of the article.
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Dosages should be quoted in metric units.

Laboratory values should be in SI units with traditional unit in parentheses.

Do not use patients' names, initials or hospital numbers to ensure anonymity.

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Tan and Ho. Treat-to-target approach in managing modifiable risk factors of patients with coronary heart disease in primary care in Singapore: What are the issues? *Asia Pacific Family Medicine*, 2011; 10: 12. doi:10.1186/1447-056X-10-12.

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Circulation

The Singapore Family Physician is published quarterly. It is circulated to all Fellows, Collegiate Members, Ordinary Members and Associate Members of the College of Family Physicians Singapore, and to private and institutional subscribers. It is also published online and can be found at www.cfps.org.sg

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The Social and Healthcare Service Directory

2011/2012 is a collaborative effort between the Centre for Enabled Living (CEL) and Agency for Integrated Care (AIC). It is designed to provide easy access to social and health-related information and services, without the need to go to multiple sources for information.

The directory is divided into three main sections:

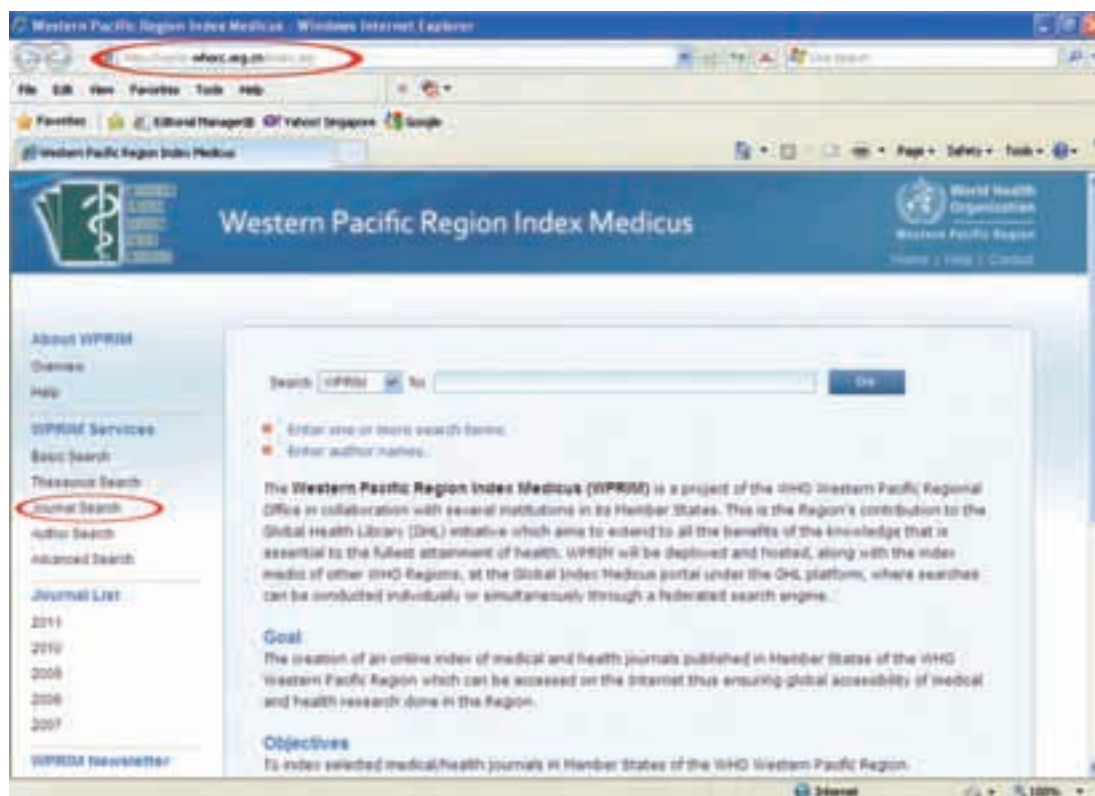
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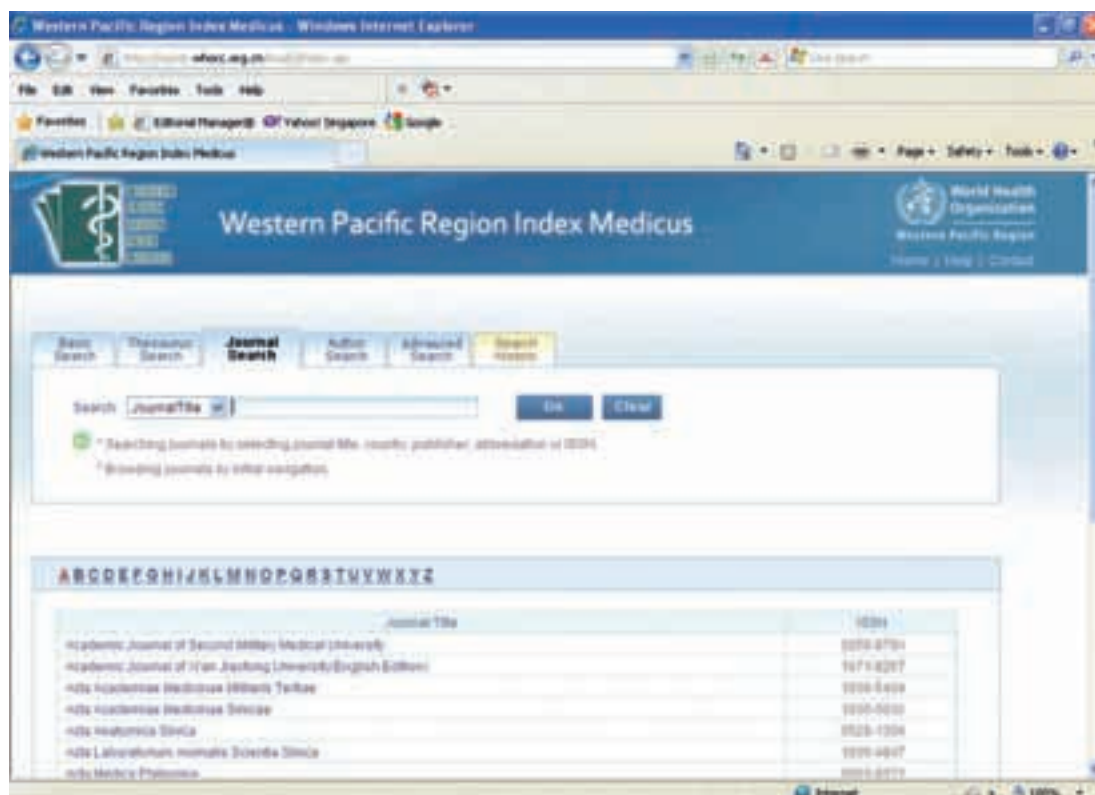
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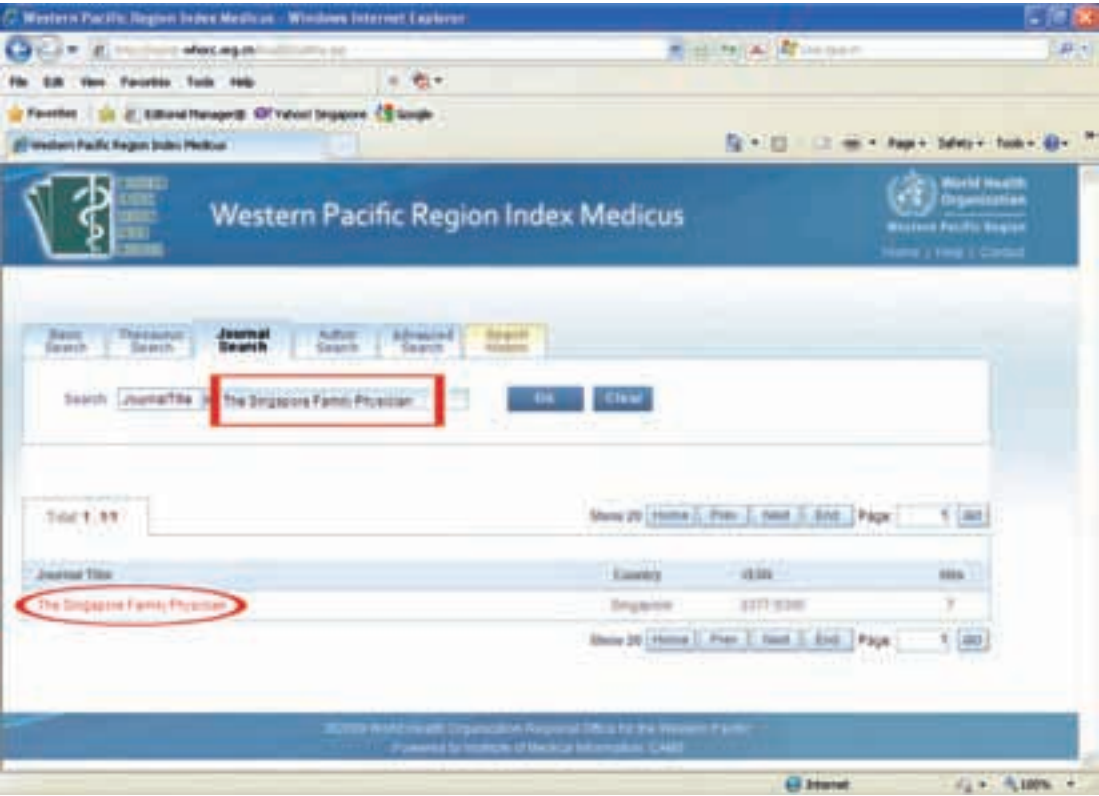
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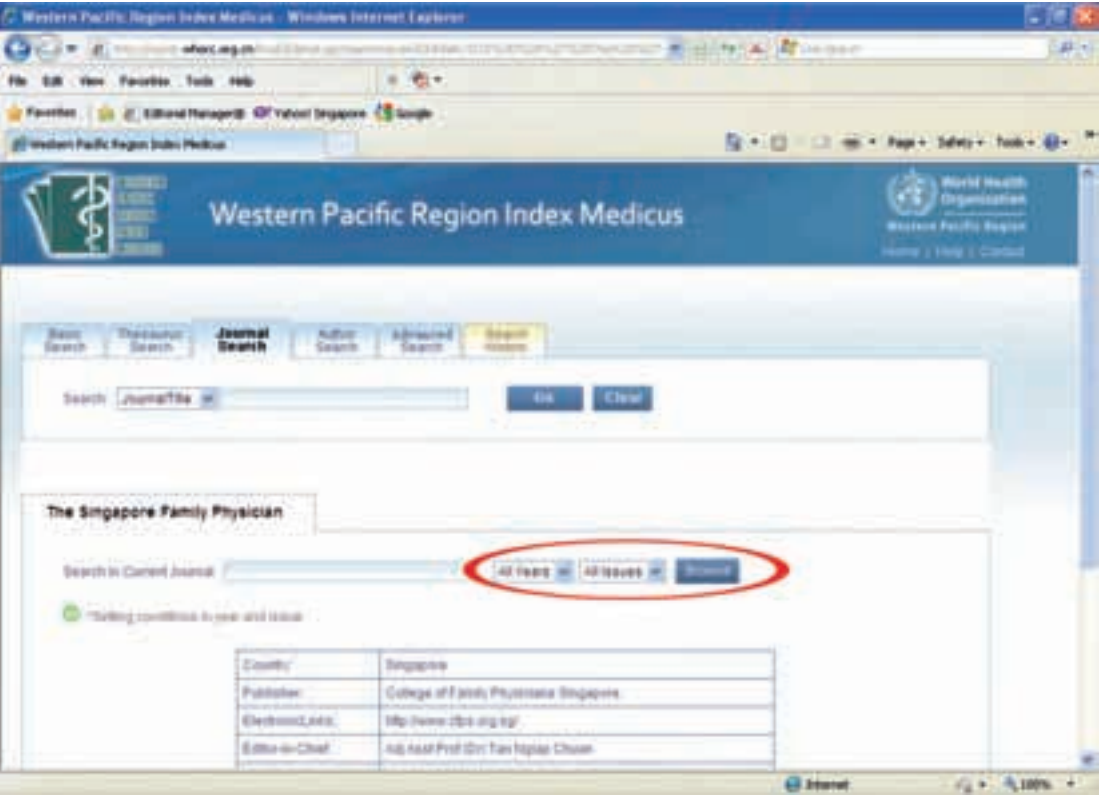
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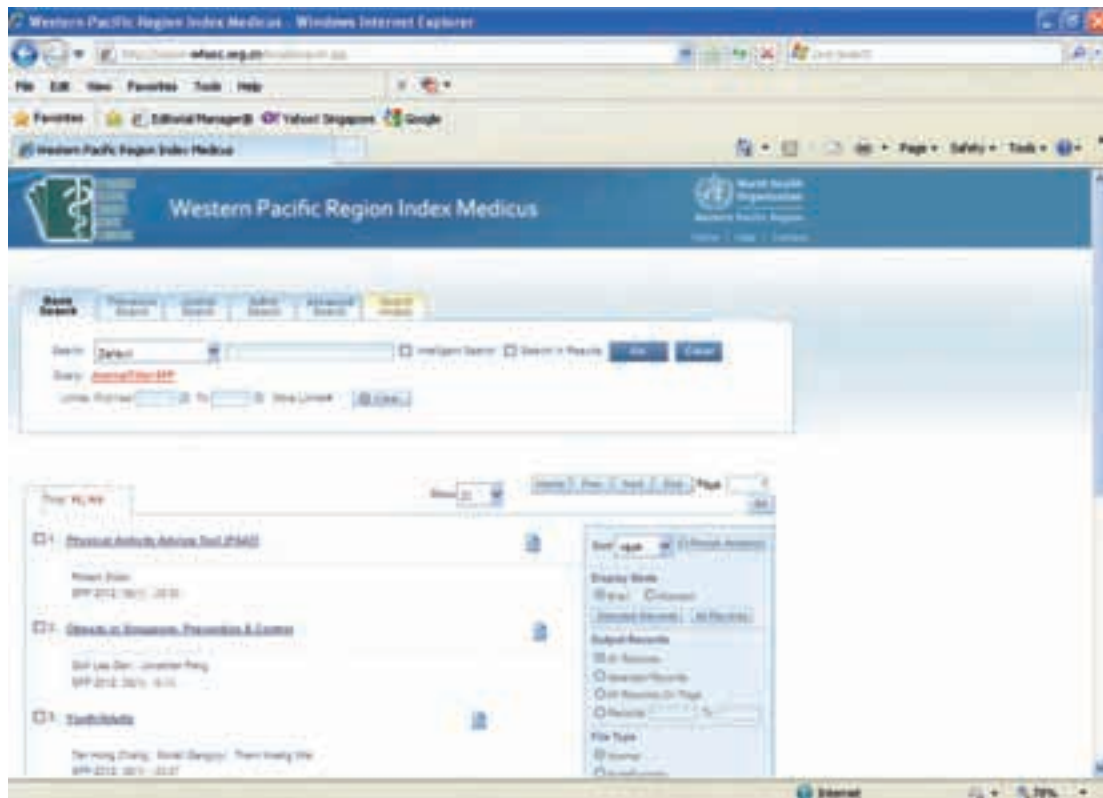
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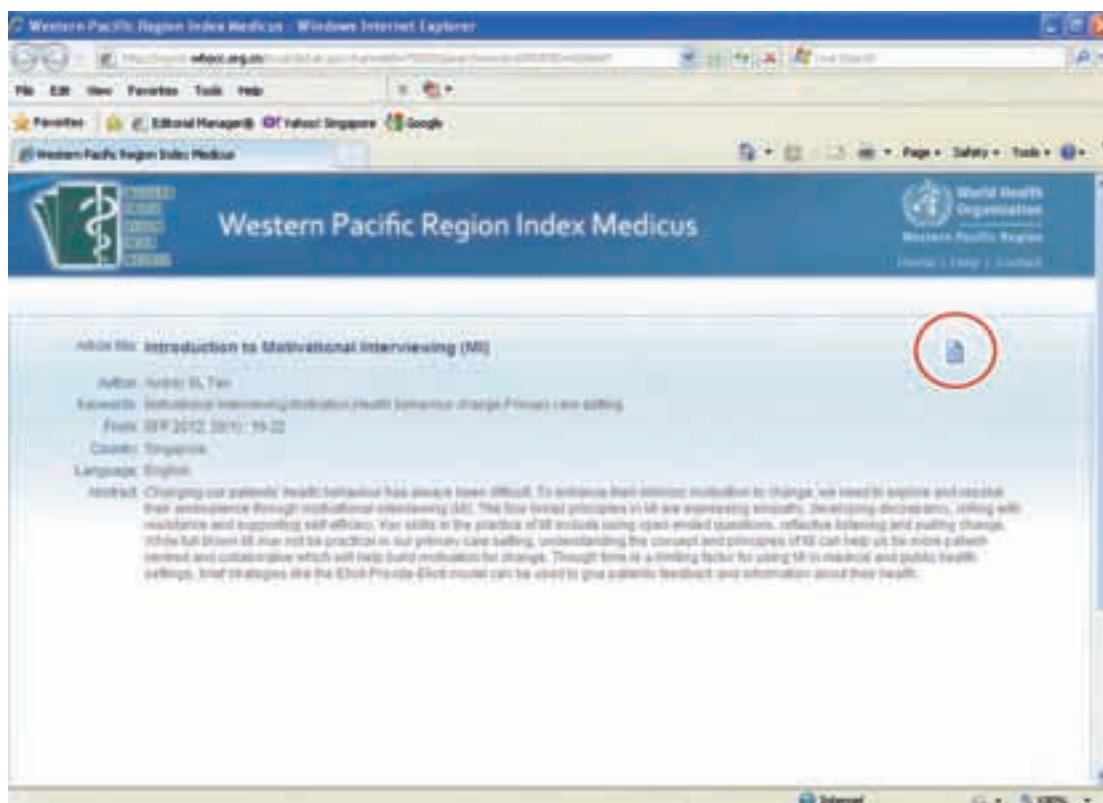
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Centre for Enabled Living is the one-stop centre that provides centralised information and referral services, administers various eldercare and disability schemes, and promotes understanding and acceptance of persons needing care* as integral members of an inclusive society.

**Persons needing care refer to frail seniors and persons with disabilities.*

Our Assistive Schemes are classified into financial and non-financial schemes.

Financial Schemes

1. Assistive Technology Fund (ATF)
2. Caregivers Training Grant (CTG)
3. Computer Access Trust Fund (CATF)
4. "LTA Cares" Fund
5. Special Assistance Fund (SAF)
6. Special Needs Savings Scheme (SNSS)
7. Traffic Accident Fund (TAF)

Non-Financial Schemes

1. Car Park Label Scheme (CPLS)
2. Foreign Domestic Worker Levy (FDWL) Concession for Persons with Disabilities Scheme



Incorporated in November 2008, **The Centre for Enabled Living (CEL)** is the national social care co-ordinator for persons needing care* and their caregivers.

It is the one-stop centre that provides centralised information and referral services, administers various eldercare and disability schemes, and promotes understanding and acceptance of persons needing care as integral members of an inclusive society.

**Persons needing care refer to frail seniors and persons with disabilities.*

Our Vision

We **build an inclusive society** where persons needing care have opportunities and access to **live life with dignity**.

Our Mission

- We **enable** persons needing care and their caregivers to make informed choices by matching individual needs with available services.
- We **coordinate** social services to strengthen the national support network for persons needing care.
- We **promote** understanding and acceptance of persons needing care as integrated members of the community.

Our Core Values

1. **Care** – Being attentive to the needs of the people we work with and serve, stakeholders and colleagues
2. **Empathy** – Putting ourselves in the shoes of the people we work with and serve to understand their needs and points of view
3. **Learn** – Engaging in continuous learning and improvement