

*Adults with Cerebral Palsy
A Rapidly Growing Population with
Complex Health Issues*

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CEREBRAL PALSY

- Umbrella term for a range of motor and cognitive disorders resulting from an injury to the brain *in utero*, during birth or up to 2 or 3 years of age.
- Etiologies include maternal infection/fetal inflammation, stroke or trauma.
- May include epilepsy, autism, and/or hearing and visual disturbances.
- **Most** have normal or superior intelligence



Epidemiology

- Developed world, prevalence estimated at 2-4 cases/1000 live births.
- Annual incidence in US is estimated to be from 8,000 to 16,000 new cases.
- Incidence of CP has been increasing over the last two decades.



How has Cerebral Palsy Changed?

ETIOLOGY

- Historically: infection with the Rubella virus (German measles) *in utero* and kernicterus (Rh incompatibility)
- Today: major association is low-weight prematurity:
 - Periventricular leukomalacia
 - Intraparenchymal hemorrhage
 - Other



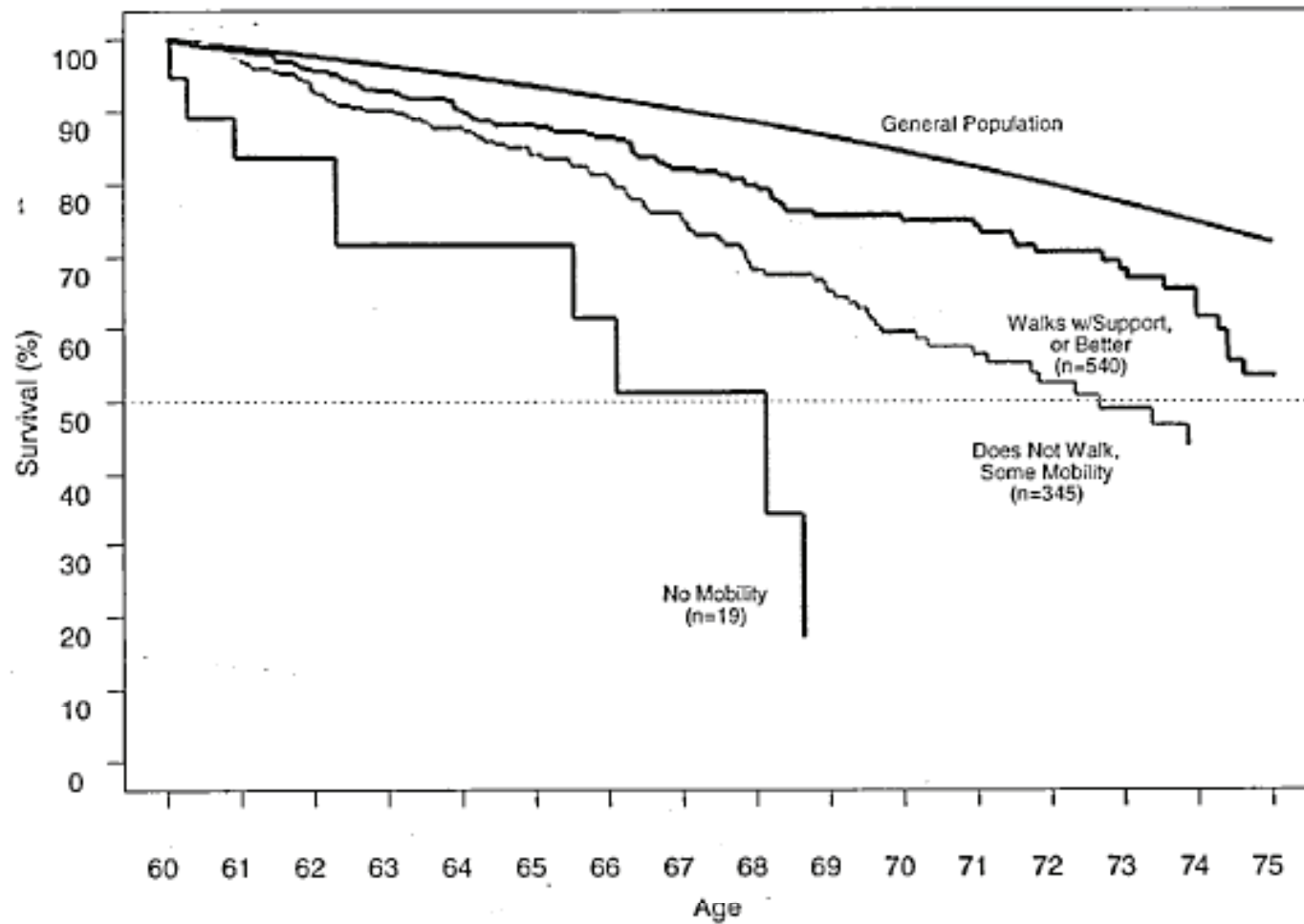
How Has Cerebral Palsy Changed?

PREVALENCE

- **Most** individuals now living well in adulthood (predictors include severity of disability and cognitive level)
- Prevalence of CP is increasing due to increased survival of low-birth-weight infants and increased longevity of adults
- Exact number of individuals in US unknown, **estimate** 700,000 to 1 million



MORTALITY



Strauss et al, Nuero R, 2004



SECONDARY COMPLICATIONS IN THOSE AGING WITH CP

- Adults with CP experience a premature ‘aging’, with chronic pain, extreme fatigue, osteoporosis, and osteoarthritis – resulting in an early loss of ambulation and independence
 - In one study clinical evidence of arthritis was found in 27% of subjects with CP ages 15-25
 - 67 to 84% of adults with CP report chronic pain
 - One study of pain and mobility indicated that of 75% of 101 individuals with CP who were ambulatory stopped walking by age 25 due to fatigue and walking inefficiency and the majority of the rest of the subjects stopped walking by age 45 due to pain in the weight bearing joints
- Unclear about increased diabetes/obesity/CVD – but commonly occur in conditions with reduced mobility, e.g., SCI



WHY IS 'PREMATURE AGING' OCCURRING?

- Wrong or inadequate childhood interventions for spasticity, hip dysplasia, abnormal gait, etc
 - Many treatments are based on anecdote and tradition rather than strong scientific evidence
- Lack of weight bearing exercise through adulthood
- Some medications to treat epilepsy can cause osteopenia
- Abnormal joint morphology and thin cartilage seen in individuals with CP lead to early degeneration
- Physical Inactivity
- Lack of medical attention/physical therapy after childhood



KNOWLEDGE GAPS – EPIDEMIOLOGY OF ADULTS WITH CP

- Natural history of pathologies and impairments associated with CP through-out the lifespan
- Age-Specific Prevalence of CP
- Age- Specific Prevalence of Secondary Conditions
 - How is the development of secondary conditions influenced by an individual's sex, GMFCS level, subtype of cerebral palsy (spasticity, dystonia, hyperkinesias), etc?



KNOWLEDGE GAPS - HEALTH SERVICES FOR ADULTS WITH CP

- There is a dearth of evidence based knowledge for the best prevention and intervention strategies to prevent the consequences of aging with CP (loss of mobility, independence)
- Access to treatment/rehabilitation drops off precipitously after high school for many individuals with CP – lack of continuity of care
- Most physicians have no idea how to treat secondary complications of CP in the adult
- Should move to a system of health services to maximize life-long functioning of disabled rather than to just a new health care environment



KNOWLEDGE GAPS – HEALTH OUTCOMES FOR ADULTS WITH CP

- We don't know which treatment and intervention strategies will be most successful in preventing secondary musculoskeletal and neuromuscular conditions associated with aging with CP
- There is a lack of information on the long-term outcomes of early interventions including
 - Exercise therapies, Orthotics, Anti-Spasticity Treatment, Anti-Epileptic Treatments, Surgery



NEEDED -CLINICAL RESEARCH FOR ADULTS WITH CP

- Promote research on methods to conserve, protect and restore musculoskeletal and neurologic function.
 - What is the effectiveness of current interventions, such as exercise, muscle strengthening, nutrition, gait training, and other modalities in promoting health and wellness and preventing musculoskeletal and neuromuscular impairments, loss of ambulation and resulting secondary medical conditions in adults with cerebral palsy?
 - How aggressively and how early should these prevention strategies be pursued?
- Investigate neurorehabilitation modalities and technologies that may help improve functionality, or at least minimize secondary complications seen in the adult with cerebral palsy.
 - What is the capacity for neural plasticity in the adult with cerebral palsy?
 - Can we apply the same principles established for experience dependent neural plasticity in stroke rehabilitation to cerebral palsy?



NEEDS-CLINICAL RESEARCH FOR ADULTS WITH CP

- Is there a role for neurorehabilitation modalities such as mass practice/robotics, transcranial magnetic stimulation, virtual reality and neuromuscular stimulation that have shown benefits in patients with stroke and/or spinal cord injury in the treatment of both children and adults with CP?
 - Can they help develop new locomotion and functional skills?
 - Will this lead to reduced muscle atrophy and increased muscle strength?
 - Do they have a role in osteoporosis prevention?
 - Will they exacerbate osteoarthritis or can the intervention be designed to prevent it from occurring?
 - Will they be effective in preventing contractures, pain, and lessening fatigue and spasticity?
 - Will they prevent the metabolic repercussions of inactivity such as metabolic syndrome, depression, cognitive decline and loss of cardiovascular fitness?



MIDDLE EAST RESEARCH CONSORTIUM

- Began in 2005
- USAID funded research with CPIRF oversight
- Researchers, clinicians and CP patient populations from Jordan, Israel and Palestinian Territories
- Increased access to care and therapy for children with cerebral palsy in the region.
- New collaborative clinical and medical academic relationships have been founded and sustained in Jordan and Israel.
- Rigorous clinical data has been collected
- New discoveries relevant to physical therapy interventions have been found.



MIDDLE EAST STEPPING FORWARD (MESF)

- Researchers, patient populations and clinicians from Israel, Palestinian Territories, Jordan, Morocco and Egypt participating
- Oversight – CPIRF Scientific Advisory Council
- Funding – Private
- Specific Aims
 - To survey the present status of rehabilitation of individuals with CP in the participating countries to obtain and compare current standards
 - To compare the efficacy of two rehabilitation technologies to facilitate neural reorganization, and improve walking in real life situations
 - To disseminate research tools and treatment approaches in the regions and the formation of a working group to develop multi-national and local programs in each country
 - To expand collaborative research and education efforts between Arab countries and Israel pertaining to adolescents and adults with physical disabilities through sharing of skills and knowledge.



MIDDLE EAST STEPPING FORWARD (MESF)

○ By-Products of Research Consortium

- Develop local experts to serve as trainers to their colleagues and teach the use of measures, tests and newly developed methods of interventions in populations with brain damage and movement disorders. The researchers will continue to teach, use and evaluate these methods in their countries after this specific project is completed.
- Develop research role models: clinicians and populations with movement disorders can function as “promoters of peace” and demonstrate scientific and medical development in the region.



CHAOTIC PERTURBATION FOR PREVENTION OF FALLS IN ELDERLY

- **SMILING (SELF MOBILITY IMPROVEMENT IN THE ELDERLY BY COUNTERACTING FALLS)** is an Israeli (Step of Mind Device) initiative to develop a system that will chaotically induce small perturbations for elderly to prevent falls.
- Initiative started by Simona Bar-Haim, Phd, from success with children with CP in MERC project
- Involves an algorithm for training walking with perturbations and components of Motor Learning.
- Funded by the EU commission's 7th RTD framework, the largest R&D program in the world.
- SMILING is funded at 2,400,000 EURO for the whole consortium.
- Participating countries include Israel, Italy, the Netherlands, France, the UK and Slovakia



THANK YOU FOR YOUR ATTENTION !

