
POSTER ABSTRACT

CPUP- A multidisciplinary secondary prevention program for individuals with cerebral palsy

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Introduction: Cerebral palsy (CP) is one of the more common early onset disabilities. CP is lifelong and associated with musculoskeletal complications and reduced participation in society. The causal brain damage is non-progressive but many associated secondary conditions develop and worsen over time. Levels of function and comorbidities vary greatly; some individuals with CP function independently, whereas others experience severe limitations and require full-time assistance. Numerous treatments and medical procedures are used to maximize physical function such as physical and occupational therapy, orthoses, medications, and orthopedic surgeries.

Short description of practice change implemented: The Cerebral Palsy Follow-Up Program (CPUP) is a combined follow-up program and national quality register that was initiated in southern Sweden in 1994. Since 2007, all habilitation units in Sweden participate. Follow-up schedules for physical therapy, occupational therapy and hip x-rays are based on age and gross motor function. The program is also used in Norway, Denmark, Scotland, and parts of Iceland and Australia.

Aim and theory of change: In CPUP, we believe that preventive care is preferable to reactive care. CP requires coordinated multidisciplinary care. Numerous professions are involved such as neurologists, orthopedic surgeons, hand surgeons, physical therapists, occupational therapists, nutritionists, and psychologists.

Targeted population and stakeholders: Children and adults with CP, their families, healthcare practitioners, and supervisors.

Timeline: CPUP is fully implemented in Sweden and has become integrated into the regular care of individuals with CP. Adults with CP became eligible to participate in 2011.

Highlights: To date, 5,400 individuals are participating in CPUP in Sweden. In addition to being a tool to organize and structure healthcare, CPUP is providing a vast database for research. Currently, 57 peer-reviewed articles have been published based on CPUP data. Since the initiation of CPUP, hip dislocations have been reduced from 10% to 0.4%, and contractures have been significantly reduced. In 2015, the CPUP User Board was created, which consists of individuals with CP as well as family members.

Comments on sustainability: The program is now part of the regular care children and adolescents receive at the habilitation units. Every year, an annual CPUP meeting is organized where professionals and users meet and network and learn about new research and changes in the program.

Comments on transferability: The program can be transferred to different diagnoses and contexts. The follow-up program for myelomeningocele MMCUP has largely been based on CPUP.

Conclusions (comprising key findings): Hip dislocations and contractures have been significantly reduced.

Discussions: Professionals and supervisors are positive about the program and report that it has facilitated their work by making sure that the patients get appropriate treatment in a timely manner, that patients get similar care regardless of geographic location, and that it has improved multidisciplinary collaboration.

Lessons learned: Start small and scale up over time. Be stringent on what variables to measure to avoid overwhelming both professionals and patients. Involve users to ensure that what the professionals find important are also important to those living with CP. Feedback and development through annual meetings with all people involved are helpful.

Keywords: cerebral palsy; registry; secondary prevention; follow-up
