

National cerebral palsy minimum data set

INTRODUCTION

Cerebral palsy (CP) is the most common chronic motor disability and neurological complication in children and occurs due to a nonprogressive lesion in the developing brain.^[1] Physically handicapped are one of the less frequent but the most different groups among exceptional children. CP is the most common motor disability in children after mental injuries, and the incidence of CP is about 2/1000 live births in Europe.^[2]

Considering Iran, there is a lack of new and up to date information about prevalence and incidence of CP, CP registry system, and a minimum data set (MDS) whose data is fed into registry system.

According to standards of the Joint Commission on Accreditation of Health Care Organizations, one of the criteria for selecting an information system is uniform data definition such as a MDS and standard classifications.^[3] The MDS is a standard tool for data collection and establishment of CP informal system that is a part of health information system in society. CPMDS will create a common language for collecting integrated, accurate, and exact data. Electronic use of data and classification standards will facilitate data exchange. Access to a single source of patient's data, as well as fast follow-up procedures, can help to monitor treatment and medical outcomes along with identifying the most effective treatment. Integrated and comprehensive collection of data helps to identify prevalence and incidence of diseases, current status of patients and health care centers, priorities and needs for future preventive, control, and treatment activities. The CPMDS aims to collect the most accurate and complete data to monitor CP, identify interventions that can affect patients' quality of life, discover treatment methods, and evaluate preventive strategies for involved people and their families. In addition, use of this information in treatment and care of children with CP allows families to share information between members and care team.^[4-6]

Cans *et al.* in a study entitled "CP registries" concluded that America, Canada, and Australia have information systems for recording CP information. In addition, in Europe, there are 18 registry or CP information centers that try to coordinate the data through a European Network. Collection of this information is useful in monitoring CP process, decreasing CP prevalence, and discovering the causes of CP.^[7]

Ghasemof in his study "comparative study of risk factors of CP between 2008 and 2010 in Shiraz in Motahari Clinic Shiraz," concluded that data elements on pregnancy, delivery method, size of the baby's head, reason for baby's admission, newborn jaundice, and prematurity are among important CP risk factors while during birth and after birth factors are prevalent reasons of CP; however, access to important information and necessary data elements will lead to a CP information system.^[8]

CONCLUSION

The CPMDS can facilitate and increase access to CP patients' integrated data that is eventually fed into resulting systems. Monitoring collected data is the basis and foundation of disease progression management, identification of influencing factors, prevention, and treatment of CP.

ACKNOWLEDGMENTS

Support & Source of funds: This article resulted from part of research project No. 393203 funded by the vice chancellor for research of the School of Medical Management & Information Sciences, Isfahan University of Medical Sciences, Iran.

AUTHOR'S CONTRIBUTION

SA contributed for conducting research project, preparing, editing manuscript, approving the final version of the manuscript. AAM contributed for collecting data, preparing, editing manuscript, approving the final version of the manuscript.

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