

Clinical evaluation of disabled children in Al-Qassim region, Saudi Arabia

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ABSTRACT

Objectives: The study was conducted as part of an overall evaluation for an outreach program to evaluate the clinical status of all the participating children, identify management problems, if any, and offer relevant recommendations.

Methods: All the participating children were subjected to a detailed clinical evaluation using a structured questionnaire developed for the purpose. The subjects of this study were registered in the Center for Disabled Children in Buraidah and Unaizah, Al-Qassim region, Kingdom of Saudi Arabia. This study was conducted in 1998 to include all registered children in the centers, which were established in 1994.

Results: One hundred and eleven children were evaluated, 51.8% were males. Average age was 72.31 months (standard deviation 32.99). The children fell into 3 diagnostic groups: Cerebral palsy (CP) group (n=41), chromosomal abnormalities group (n=36) and

miscellaneous group (n=34). Mothers were the direct caregivers in 98.1% of cases. The sample as a whole suffered from a number of disabilities, the most common of which was severe speech difficulty (88.3%). Fifty seven percent of the children were severely malnourished. The CP group suffered most, as they were significantly fewer mobiles and more dependants on the care-giver. History of neonatal asphyxia and severe malnutrition at the time of examination were also significantly more common in this group.

Conclusion: This group of disabled children is enjoying a comprehensive rehabilitation service delivered through an efficient outreach program. It was observed that the families need extra support to improve mobility, nutrition and communication abilities of the participating children.

Neurosciences 2002; Vol. 7 (4): 272-277

The prevalence of childhood disability has been adequately documented by several studies in Al-Qassim Region in particular, in Kingdom of Saudi Arabia (KSA) in general and indeed all over the world.¹⁻⁵ Disabled children suffer from physical, mental, psychological and social problems, and they are likely to be disadvantaged, have reduced life span and probably abused.⁶⁻⁹ The families are frustrated by being unable to respond to the needs of their little ones who are growing bigger everyday and getting more difficult to handle. In some parts of the world,

the problem of disabled children was neglected due to lack of accurate information and lack of expertise in identifying and managing the cases. In those areas there was, until recently, a general belief that treatment is difficult and expensive with limited success if any. Hence the problem was accorded a low priority.¹⁰ Historically it was Little,¹¹ an Orthopedic Surgeon, who gave the first detailed clinical description of cerebral palsy (CP). In 1861 he was the first to postulate an etiological relationship between neonatal asphyxia and CP when

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Received 28th October 2001. Accepted for publication in final form 20th March 2002.

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he claimed that "the act of birth did occasionally imprint in the nervous and muscular system of the nascent organism very serious and peculiar evils".¹¹ His footsteps were followed by dedicated Orthopedic Surgeons like Dr. Winfield Phelps, who actually popularized the term CP, concentrating on the surgical case management of the motor deficit.¹² This institution-based management was the norm until very recently when it was realized that the problem is much more than the motor deficit. The mental, psychological, social and communication aspects needed much more attention.^{13,14} The modern concept of the holistic approach to rehabilitation as outlined in the World Health Organization (WHO) publication¹⁵ broadened the approach beyond the pure motor deficit focus to include a wider range of function like communications and vocational training. Also, major strategies were modified from institution-based rehabilitation to outreach rehabilitation and community-based rehabilitation. Although, such programs have been recommended by WHO for implementation in developing countries as an antidote for poor coverage, it was claimed that implementation was disappointing, stressing the need for developing favorable attitudes among rehabilitation workers and encouraging community development as possible solutions.^{16,17} In this paper, we report the clinical evaluation of children registered in a home based outreach rehabilitation program started in Al-Qassim region in 1994.¹⁸ The clinical evaluation was carried out as part of a full evaluation of the various activities of this program.

Methods. The subjects of this study included all the children registered in the Centers for Disabled Children in Buraidah and Unaizah, Al-Qassim Region, Central KSA. This study was conducted in 1998. These centers were established in 1994 as an outreach program in an attempt to improve the services to disabled children in the 2 cities. The program was delivered as an innovative intervention offering continuous health education to mothers of disabled children through regular and frequent home visits by dedicated nurses.¹⁸ At the start of the intervention, the nurses were selected from a pool of female hospital nurses who were of Saudi nationality. They were offered an intensive training course designed to enable them to educate the mothers on how to cope with the needs of their disabled children. Each of the nurses was assigned to one or other of the centers that she uses as her base and where all her records are kept. Each of the centers was supervised by a General Supervisor, whose job is to coordinate the home visits, supervise the nurses and monitor their activities. She also gives technical support whenever that is needed and discharges the day to day administration of the center. A structured questionnaire was specifically developed for the purpose of the present study which

was pilot-tested by the 2 authors who conducted the clinical examination. The findings were discussed by the research group and the necessary modifications made until the group was satisfied with the validity and reliability of the data collection tools. Each of the children registered in one of the centers was given an appointment to come to the center where clinical evaluation was carried out in the presence of the assigned home visiting nurse. The result of the evaluation including a detailed history and a thorough clinical examination was entered in the prepared questionnaire. The child was then referred to the Pediatric clinic in the Regional Referral Hospital where the same doctor reviewed the hospital charts, decided on referral for specialized clinical examination (for example, eye, nose and throat [ENT] and Ophthalmology) if needed, and ordered relevant investigations for each child. All the relevant data was recorded by the examining physician on the prepared questionnaire and then coded for computer entry.

Definitions. For the purpose of this report the following definitions were used: Cerebral Palsy - includes children who, on clinical evaluation were found to have non-progressive impaired motor function that was probably due to an insult to the central nervous system that occurred either before or at the time of delivery or in early childhood.¹⁹ Chromosomal abnormalities - includes children showing clear clinical features of recognized clinical and or laboratory evidence of chromosomal abnormalities for example Down's Syndrome. Developmental delay - was assessed against the Denver II Screening Test. The milestones were ascertained from the mother as part of the developmental history. The delay was described as being gross motor, fine motor or visual, hearing or speech, or social. If the delay involved all the 4 parameters then it was described as Global.²⁰ Nutritional status - the child was described as being malnourished if he was clinically obviously wasted or his weight was below 80% of the 50th centile for age of the National Center for Health Statistics Growth Chart.

Statistical analysis. Data was entered and analyzed using Statistical Package for Social Sciences (SPSS) version 10 where Chi-square and Fisher's exact test were used to test the significance of qualitative data and ANOVA to test the significance of quantitative data.

Results. One hundred and eleven children were included in this study, 51.8% (57) were boys. Their ages ranged from 13 months to just over 13 years with an average of 72.13 months (standard deviation [SD] 32.99 months). **Table 1** gives the frequency distribution of some of the major presentations of these children. **Table 2** shows the major presentation of the children described under the following

Table 1 - Frequency distribution of important variables.

| Variable | n (%) |
|--|-----------|
| Informer | |
| Mother | 91 (85.5) |
| Mother & Father | 13 (12.3) |
| Other | 2 (1.9) |
| Continent | |
| No | 71 (64) |
| Yes | 40 (36) |
| Mobility | |
| On his own | 65 (58.6) |
| With assistance | 22 (19.8) |
| Fully dependent | 23 (20.7) |
| Personal needs | |
| Independent | 13 (11.7) |
| Partially | 33 (29.7) |
| Fully dependent | 65 (58.6) |
| Development in the first year | |
| Normal | 3 (2.7) |
| Mild | 24 (21.8) |
| Moderate | 42 (38.2) |
| Severe | 41 (37.3) |
| Type of developmental abnormalities | |
| Gross motor | 6 (5.6) |
| Hearing and speech | 11 (10.2) |
| Global | 91 (84.3) |
| Seizures | |
| No | 84 (75.7) |
| Yes | 22 (19.8) |
| Asphyxia | |
| No | 63 (67) |
| Yes | 31 (33) |
| Consanguinity | |
| None | 68 (62.4) |
| 1st degree | 24 (22) |
| 2nd degree | 13 (11.9) |
| Far relative | 4 (3.7) |
| Family history of disability | |
| No | 81 (73) |
| Yes | 27 (24.3) |
| Temper tantrum | |
| No | 80 (72.1) |
| Yes | 31 (27.9) |
| PICA | |
| No | 84 (75.7) |
| Yes | 27 (24.3) |
| Speech difficulty | |
| No | 13 (11.7) |
| Yes | 98 (88.3) |
| Antenatal care | |
| No | 24 (21.6) |
| Yes | 87 (78.4) |
| Place of delivery | |
| Hospital | 97 (87.4) |
| PHC | 10 (9) |
| Private | 2 (1.8) |
| Home | 2 (1.8) |
| Type of delivery | |
| Abdomen | 22 (19.8) |
| Spon. vertex | 82 (73.9) |
| Assist ceph | 7 (6.3) |
| History of Jaundice | |
| No | 64 (65.9) |
| Mild | 9 (9.3) |
| Phototherapy | 20 (20.6) |
| Exchange transfusion | 4 (4.1) |
| Malnutrition | |
| No | 45 (42.5) |
| Yes | 61 (57.5) |

n - number, PHC - Primary Health Care, PICA - "compulsive craving to eat non-food items", Spon. - spontaneous, Assist ceph - assisted cephalic

diagnostic groups. In CP group (n=41) 80.2% were spastic, 70.7% were quadriplegic, 14.6% were paraplegic and 14.6% were mixed.¹² In chromosomal abnormalities group (n=36) Down's Syndrome constituted 69.4% while the remainder were due to other chromosomal abnormalities and in the miscellaneous group (n=34) included a variety of diagnoses like degenerative brain disease,⁵ familial,⁵ metabolic abnormalities,² meningomyelocele,² microcephaly,¹ arthrogryposis multiplex,¹ and spinal muscular atrophy.¹ There were 17 children in whom diagnosis could not be reached. In addition to the features shown in **Table 2** it was observed that behavior disorders like temper tantrums were relatively common in the study sample without any predilection to a particular diagnostic group. Speech difficulty was extremely common in the study sample as a whole with an overall prevalence of 88.3%. Although the CP group has a slightly higher prevalence with 92.7%, followed by the chromosomal group with 88.6% and the miscellaneous group with 82.4%. These differences were not significant. Urinary incontinence was relatively common with the highest prevalence in the chromosomal group (54%) followed by the CP group (52.2%) and the miscellaneous group (47.1%). These differences were not significant.

Discussion. Community based rehabilitation (CBR) has been recommended by the WHO with the aim of involving the families of the disabled in the rehabilitation process. This has been adopted in different parts of the world with varying degrees of enthusiasm and success. A report from China²¹ claims that community based rehabilitation is the ideal means whereby rehabilitation for all can be achieved, while a study from Ghana¹⁷ reports disappointment with the implementation of such programs. On the other hand in some areas of Japan, where the outreach rehabilitation is available on request it is reported that only 36% of care-givers used such services while the majority continued to rely on the institution based services.²² In Vietnam, a recently reported evaluation of CBR activities found application strengths in only 3 of the 5 principles of the WHO model for²³⁻²⁴ meeting the needs of persons with disability. The program in Al-Qassim is a pioneering interventional activity initiated in 1994 where outreach services were made universally available to the disabled childhood population in the 2 major cities of the region. The results communicated in this report focus on the clinical evaluation of the children recruited in the program. It was found that in 98.1% of the cases the mother was involved in direct care giving to the child. This is expected as it is the social norm in this community and also the home visiting program which targeted the mother during the education process. It is of interest to note that the strong presence of mothers

was similar to the findings of a report from Japan where the mothers were the care-givers in 97% of the cases.²² The centers for disabled children are very much community friendly and they observe all the cultural requirements for attendance of the mother to the clinic. This promoted a strong attachment between the mother and her disabled child where it was observed that she was keenly interested in the child's welfare. On the other hand the nurses were quite conversant with the needs and problems of the child in question. Mobility of the child, his ability to

perform his own needs and urinary continence are 3 features that are important for the care-giver as they contribute a lot to the care-giver's workload. It was observed in this group that those who had attained urinary bladder continence were few (36%)¹⁹ while children in the CP group had significantly lower attainment of 22% when compared with the other 2 groups ($p < 0.05$). More than 40% of the children were either completely immobile or needed assistance, while only 11.7% were completely independent in the performance of their daily needs. These 2

Table 2 - Some of the variables as seen in the 3 diagnostic groups.

| Variable | Cerebral palsy n (%) | Chromosomal n (%) | Miscellaneous n (%) | P value |
|------------------------------------|-------------------------|----------------------|------------------------|---------|
| Continent | | | | |
| No | 32 (78) | 22 (62) | 16 (47) | |
| Yes | 9 (22) | 13 (38) | 18 (53) | |
| Total | 41 (100) | 35 (100) | 34 (100) | 0.021 |
| Mobility | | | | |
| On his own | 12 (29) | 27 (79) | 25 (73) | |
| With assistance | 13 (32) | 4 (12) | 5 (15) | |
| Fully dependent | 16 (39) | 3 (9) | 4 (12) | |
| Total | 41 (100) | 34 (100) | 34 (100) | - |
| Personal Needs | | | | |
| Independent | 1 (2) | 4 (11) | 8 (24) | |
| Partially dependent | 6 (15) | 17 (48) | 9 (26) | |
| Fully dependent | 34 (83) | 14 (40) | 17 (50) | |
| Total | 41 (100) | 35 (100) | 34 (100) | - |
| Development in first year | | | | |
| Normal | - (0) | 1 (3) | 2 (6) | |
| Mild delay | 4 (10) | 8 (24) | 11 (32) | |
| Moderate delay | 11 (27) | 21 (61) | 10 (30) | |
| Severe delay | 26 (63) | 4 (12) | 11 (32) | |
| Total | 41 (100) | 34 (100) | 34 (100) | - |
| Type of developmental delay | | | | |
| Gross motor | 3 (8) | - | 3 (10) | |
| Hearing & speech | - (0) | 1 (3) | 10 (30) | |
| Global | 38 (92) | 32 (97) | 20 (60) | |
| Total | 41 (100) | 33 (100) | 33 (100) | - |
| Seizures | | | | |
| No | 25 (63) | 27 (84) | 31 (94) | |
| Yes | 15 (37) | 5 (16) | 2 (6) | |
| Total | 40 (100) | 32 (100) | 33 (100) | 0.023 |
| Hist. of neonatal asphyxia | | | | |
| No | 15 (44) | 23 (74) | 25 (86) | |
| Yes | 19 (56) | 8 (26) | 4 (14) | |
| Total | 34 (100) | 31 (100) | 29 (100) | 0.008 |
| Consanguinity | | | | |
| None | 25 (61) | 25 (73) | 18 (53) | |
| 1st degree | 12 (29) | 7 (21) | 5 (15) | |
| 2nd degree | 3 (8) | 1 (3) | 9 (26) | |
| Far relative | 1 (2) | 1 (3) | 2 (6) | |
| Total | 41 (100) | 34 (100) | 34 (100) | 0.047 |
| Nutritional status | | | | |
| Normal | 7 (17) | 18 (58) | 20 (59) | |
| Malnourished | 34 (83) | 13 (42) | 14 (41) | |
| Total | 41 (100) | 31 (100) | 34 (100) | 0.001 |
| n - number, Hist. - History | | | | |

features were also significantly more frequent in the CP group when compared with the other 2 groups. The implication is that the care-giver was expected to cope with an extra load looking after the daily needs of these children for some years, therefore attempts to improve their mobility should be helpful. Only 2.7% of the parents thought that their children were developing normally during the first year of life with 21.8% having mild delay while the rest of the parents thought their children suffered from moderate to severe delay since infancy. Severe delay was significantly more common in the CP group ($p < 0.001$). In 5.6% the delay was purely motor while in the vast majority it was global. In both, these parameters the CP group was affected significantly more frequently than the other 2 groups. In other countries where outreach rehabilitation was available on the request of the care-giver it was reported that the severity of disability contributed towards seeking help to release the burden.²² The prevalence of seizure disorders in the study sample was 19.8% which was higher than in normal children but less than expected for children with similar problems.¹⁹ However, seizures were significantly more frequent in the CP group compared to the other 2 groups ($p < 0.05$). Thirty-three percent of the study population gave a positive history of neonatal asphyxia with the CP group having a significantly higher prevalence than the other 2 groups ($p < 0.01$). This is expected, as the association between CP and asphyxia is well established.¹⁹ In 22% of the study sample there was first-degree consanguinity, which was significantly more frequent in the CP group ($p < 0.05$). Twenty percent of the sample reported that another sibling was affected with a disability. This is comparable to findings reported in other studies in KSA.² Fifty-seven percent of the children in this study were clinically malnourished. This figure compares very well with a report from Sweden on a group of children similar to this, where it was found that 43% of the children were malnourished.²⁵ We were unable to find data for Saudi children with similar disabilities. However, Al-Frayh and Bamgboye²⁶ reported that 11% of normal adolescent girls suffer from some degree of malnutrition. While Abu Hussein et al²⁷ reported that 20% of a sample of normal school children were below the 2 SD score compared to the National Center for Health Statistics Growth Chart. It is clear that the nutritional status of the children in our study is much worse, with the CP group having significantly worse nutritional status when compared with the other 2 groups ($p < 0.001$). Of the children, 29.7% had persistent temper tantrums but this is expected as behavior disorders are well known to occur more frequently with mental retardation and CP.²⁸ Likewise, compulsive craving to eat non-food items (PICA) was noted in 24.3% of the study sample. This is a feature that should not be seen in normal children beyond the age of 2 years,

but it is well known to occur with mental retardation as well as many other social problems, and can be associated with iron deficiency anemia, lead poisoning and parasitic infestations.²⁸ There was an extremely high incidence of speech problems in the study population reaching an overall prevalence of 88.3% with non-significant variation between the diagnostic groups. Many other factors were analyzed (for example antenatal care, place of delivery, type of delivery and so forth) but they were all found to be non-significant. The authors are aware that the populations of the present study are ideal for evaluation of factors such as the quality of life of the individual patient, the impact of the disability on the family, the acceptance of the problem by the family and the degree of satisfaction with the service offered.²⁹ These will be the subject of a separate communication.

Recommendations. The findings of this study suggest that the following recommendations could be implemented: 1) Mobility of the children should be improved through surgical intervention and provision of appliances. These can be coordinated with the Physiotherapy and Orthopedic Departments in the Regional Hospitals. 2) Prevalence of neonatal asphyxia was very high in this study population, this is a preventable cause of disability therefore an extra effort should be made through antenatal clinics and maternity units to reduce it. 3) There is a need for nutrition intervention to support the families of disabled children specially those with CP. 4) Actions should be started to identify speech and communicate problem in disabled children and take measures to improve that. 5) Severe parenting stress was reported in similar populations.³⁰ It could well be useful to offer relevant counseling to the families in this program. 6) Service needs assessment should be conducted regularly as it has been reported that many of the families may have some unmet needs, which they do not express voluntarily.³¹

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