

EARLY INTERVENTION FOR CEREBRAL PALSY CHILDREN

Thesis

For fulfillment of Ph.D. Degree in Medical Childhood studies

By

Madeleine Sabri Azmi

MBBCh, M.Sc.Ped

Supervised by

Prof. DR. Hamed Ahmed El –Khaiat

Professor of pediatrics

Faculty of medicine, Ain Shams University

Dr. Samia Samy Aziz
Assistant professor of
medical childhood studies
Medical Dept. Institute of
Post-graduate
Ain Shams University

Dr. Hoda yahya Tamoum
Assistant professor
of Pediatrics
Faculty of Medicine
Ain Shams University

2007

Contents

<u>1. Introduction</u> -----	<u>1</u>
<u>2. Aim of the Work</u> -----	<u>4</u>
<u>3. Review of Literature</u> -----	<u>5</u>
<u>4. Subject and Method</u> -----	<u>91</u>
<u>5. Results</u> -----	<u>101</u>
<u>6. Discussion</u> -----	<u>131</u>
<u>7. Recommendation</u> -----	<u>145</u>
<u>8. English Summary</u> -----	<u>146</u>
<u>9. References</u> -----	<u>151</u>
<u>10. Arabic Summary</u> -----	

List of Figures

<u>Fig.1</u>	<u>: Possible potentiating effects of risk factors on family interaction patterns and child development outcomes</u>	<u>9</u>
<u>Fig.2</u>	<u>: Components of Early Intervention programs as a response to stressors.</u>	<u>13</u>
<u>Fig.3</u>	<u>: Different correct ways for lifting and carrying a CP children.</u>	<u>33</u>
<u>Fig.4</u>	<u>: Different correct positions for CP children</u>	<u>35</u>
<u>Fig.5</u>	<u>: Aids to mobility of CP children</u>	<u>36</u>
<u>Fig.6</u>	<u>: Different supports used to maintain balance during personal care</u>	<u>37</u>
<u>Fig.7</u>	<u>: Oral control techniques</u>	<u>39</u>
<u>Fig.8</u>	<u>: Conceptual Model of the Care giving process among care givers of a pediatric population</u>	<u>53</u>
<u>Fig.9</u>	<u>: GMFCs level for children Before and After intervention</u>	<u>105</u>
<u>Fig.10</u>	<u>:Gross Motor Developmental age before and after intervention</u>	<u>106</u>
<u>Fig.11</u>	<u>: Gross motor developmental rate before and after Intervention</u>	<u>108</u>
<u>Fig.12</u>	<u>: Fine motor developmental age before and after intervention</u>	<u>111</u>
<u>Fig.13</u>	<u>: Fine Motor developmental rate before and after intervention</u>	<u>111</u>

<u>Fig.14</u>	<u>: Self Help developmental age before and after intervention</u>	<u>113</u>
<u>Fig.15</u>	<u>: Self Help developmental rate before and after intervention</u>	<u>115</u>
<u>Fig.16</u>	<u>: Total Parenting Stress score before and after intervention</u>	<u>120</u>
<u>Fig.17</u>	<u>: Total child domain stress score before and after intervention</u>	<u>121</u>
<u>Fig.18</u>	<u>: Parent domain total stress score before and after intervention</u>	<u>121</u>
<u>Fig.19</u>	<u>: Parental acceptability for the child before and after intervention</u>	<u>122</u>
<u>Fig.20</u>	<u>: Child demanddigness before and after intervention</u>	<u>123</u>
<u>Fig.21</u>	<u>: Child reinforcement of parent before and after intervention</u>	<u>123</u>
<u>Fig.22</u>	<u>: Parent attachment before and After intervention</u>	<u>125</u>
<u>Fig.23</u>	<u>: Parent depression before and after intervention</u>	<u>125</u>
<u>Fig.24</u>	<u>: Restrictions of parental role before and after intervention</u>	<u>126</u>
<u>Fig.25</u>	<u>: Social isolation before and after intervention</u>	<u>127</u>
<u>Fig.26</u>	<u>: Parents, sense of competence before and After intervention</u>	

List of Table

<u>Table (1)</u>	<u>: Levels of prevention: Early Intervention implication</u>	<u>15</u>
<u>Table (2)</u>	<u>: Levels of prevention: implications for early intervention policy</u>	<u>18</u>
<u>Table (3)</u>	<u>: Signs Useful in early diagnosis of CP</u>	<u>71</u>
<u>Table (4)</u>	<u>: Children's mean age, gender, and type of CP</u>	<u>101</u>
<u>Table (5)</u>	<u>: Children's age in Month at time of entry of and at the end of the program, type of cerehral palsy and their level of Mental disability</u>	<u>102</u>
<u>Table (6)</u>	<u>: The distribution of children by type of CP on the GMFCs before and after intervention</u>	<u>104</u>
<u>Table (7)</u>	<u>: Cross Motor pre-intervention and post intervention raw score, developmental rate, and change index</u>	<u>107</u>
<u>Table (8)</u>	<u>: Fine Motor pre intervention and post intervention raw score, developmental age, Developmental rate, and change index</u>	<u>110</u>
<u>Table (9)</u>	<u>: Self Help pre- intervention and post intervention raw score, developmental age, Developmental rate, and chang index</u>	<u>115</u>

<u>Table (10)</u>	: <u>Relationship between number of sessions and skills gained in Gross Motor, fine motor, and self help skills</u>	<u>115</u>
<u>Table (11)</u>	: <u>Relationship between type of CP and skills gained in the 3 domains</u>	<u>116</u>
<u>Table (12)</u>	: <u>Relationship between the age of the children at the start of the program and skills gained</u>	<u>117</u>
<u>Table (13)</u>	: <u>Parent stress total score, child domain total score and parent domain total score by type of CP and the GMFCs</u>	<u>118</u>
<u>Table (14)</u>	: <u>Percentages of parents recorded significant score on the parents stress index and its subscales before and after intervention</u>	<u>119</u>
<u>Table (15)</u>	: <u>Relationship between degree of disability and parenting stress scores and its subscales</u>	<u>129</u>

List of Abbreviation

<u>NDT</u>	<u>: Neuro Developmental Treatment</u>
<u>CP</u>	<u>: Cerebral palsy</u>
<u>EMPP</u>	<u>: Early Motor Pattern Profile</u>
<u>GMFCs</u>	<u>: Gross Motor function classification system</u>
<u>PCI</u>	<u>: Proportional change indices</u>
<u>PSI</u>	<u>: Parenting stress index</u>
<u>PRD</u>	<u>: Parent Related Domain</u>
<u>CRD</u>	<u>: Child Related Domain</u>
<u>ATNR</u>	<u>: Asymmetric tonic neck response</u>
<u>CPVL</u>	<u>: Cystic periventricular leukomalasia</u>
<u>MR</u>	<u>: Mental Retardation</u>

Acknowledgment

First, *thanks are all to GOD* for blessing this study until it has reached its end as a little part of his generous help throughout my whole life.

I find no words by which I can express my extreme thankfulness, appreciation and profound gratitude to my professor, *Dr. Hamed Ahmed El khayat*, Pofessor of Pediatrics, Ain Shams University, for his real support as well as his patience, encouragement and keen interest in accomplishment of this work. I can never thank him as much as he deserves.

I equally like to extend my sincere gratitude to my professor, *Dr. Hoda Yehya Tamoom* for her patience, noble character, and generous attitude. No words can be sufficient to express my gratitude.

I am deeply grateful to my professor *Dr. Samia Sami Aziz*, Assistant Professor in Medical Childhood Studies, Ain Shams University for her generous help and moral support in spite of her innumerable responsibilities. Her friendly attitude helped me a lot in the production of every part of this work.

I am deeply grateful to *Seti Staff*- Caritas Egypt, and *Ahmed Maher* Teaching Hospital – Early Intervention staff, for their sincere cooperation and facilities offered through the study. They all helped me so much in the production of this work.

Last but not least, I wish to thank *my family* who has all shared with me the objective of giving birth to this piece of work. They help me so much in the production of this work. They all gave me time and surround me by love and support.

Abstract

Early intervention program promote the development of young children with disabilities. As well as support the families of young developmentally disabled children to enable them to meet the needs of childhood effectively, and /or promote adaptive family functioning.

The present study aimed at investigating the effectiveness of early intervention program on the development of children with cerebral palsy. As well as assessing the impact of early intervention program on parent stress and parent-child relationship. Thirty eight children fulfilled the inclusion criteria of the study. Only 15 continued the whole intervention training year.

An individual tailored program was designed for every child after assessing the child's abilities and skills. Parents' involvement was encouraged throughout the program.

The results support the effectiveness of early intervention program in facilitating the acquisition of skills measured in the program contexts by children with cerebral palsy. On the other hand, parents who participated in the program showed better adaptation. After intervention, parents had lower level of parental distress. Early intervention not only accelerates child development but can also modify predictor-variables of stress in parents of a disabled child situation. At the end, we need to emphasize on the importance of early intervention programs to enhance the development of children with cerebral palsy. Also, Practitioners should be aware of the critical role of parent involvement for successful early intervention program .

Key words: Cerebral palsy, Early Intervention, Parent stress

Introduction

The human child is the greatest miracle of creation. Every single child is a world of subtle secrets, a personality, and a unique occurrence, never to be repeated on this earth. With child who is born under no matter what circumstances, and no matter what parents, the potentiality of human race is born again (*Mydral, 1991*).

Normal child development is the attainment of developmental landmarks or milestones within the expected age range and in comparison with children of the same age group. Children with developmental disabilities, have been defined as individuals with impairments in physical or mental abilities that are manifest before 22 years of age and resulting in functional limitations in major life activities. Mental retardation is the prototypic developmental disability; others include cerebral palsy, specific learning disabilities, pervasive developmental disorders, autism, visual or hearing impairments, and disorders of communication (*Perrin and Shonkoff, 1996*).

Cerebral palsy is the term used to describe a collection of non progressive disorders that manifest as abnormalities of motion and posture and result from CNS injury in the early periods of brain development, usually mainly as the first 3-5 years of life (*Koman, et al 2004*).

Motor function is the earliest assessable developmental process, thus cerebral palsy is usually the first identifiable

developmental disability. It is often an important marker for other developmental problems that may co-exist but are not yet manifest (***Eicher and Batachaw, 1993***).

Various methods have been used to manage children with cerebral palsy where a changing balance is struck between the positive factors of normal development and growth and the negative effect of disordered brain function, and where this balance can be favorably influenced by therapeutic intervention, physiotherapy, drug treatment and orthopedic manouvres(***Brett,1997***)

Recent emphasis has been laid on early identification of affected children, so that they can benefit from early intervention programs (***Majnemer and Shevell, 1995***).

Early intervention programs are deigned to enhance the developmental competence of participants and to prevent or minimize developmental delays. There is a growing consensus based on the best available evidence that early intervention can exert moderate positive effects (***Majnemer, 1998***).

Palmer and coworkers in 1988 found that infants with cerebral palsy participating in stimulation programs achieved higher motor score than a comparable group of infants receiving only physical therapy

Warfield, et al, (1999), found that there was significant increase in the child related stress among families of children

with disabilities during early childhood period which warrants attention by pediatrician, educators and others professionals who must evaluate the needs of families of children with disabilities for supportive services.

Aim of the work

The study aims at Assessing the impact of Portage program in combination with the WHO manual "stimulation the development of cerebral palsy children" on the development of gross motor, fine motor, and self help skills of children with cerebral palsy after 1 year of intervention program.

It also, aims at assessing the impact of early intervention services on the parent stress and child-related parenting stress.

Cerebral palsy

Definition

Cerebral palsy is a group of non progressive but often changing motor impairment syndromes secondary to lesions or anomalies of brain arising in early stages of its development (**Koman, et al 2004**). It is a static encephalopathy and excludes all progressive neurological disorders. Since motor dysfunction evolves over time as the child grows, it may give an erroneous impression of the disorder being progressive. Defining CP in terms of motor deficits should not undermine the fact that other neurological deficits are frequently associated and may in times be more disabling than the motor deficit itself (**Pratibha and Gorayas, 1998**)

Prevalence and incidence:-

Cerebral palsy (CP) is a common neurodevelopment disorder of childhood with prevalence of 2-2.5 per 1000 live births (**Stanely et al, 2000**). The exact incidence and prevalence figures from Egypt are not available. Recent advances in neonatal management and obstetric care have not shown a decline in the incidence of CP (**Nelson, 2003**). On the contrary, with a decline in infant mortality rate, there has actually been an increase in the incidence and severity of CP. The incidence in premature babies is much higher than in term babies. For the vast majority of term infants who develop CP, birth asphyxia or obstetric complications cannot be ascribed as the cause (**MacLennan, 1999**).

Pathology

Cerebral palsy results from a permanent static lesion of the cerebral motor cortex that occurs before, at, or within 2 years of birth (**Flett, 2003**). Even though the lesion itself does not change, the clinical manifestations of the lesion change as the child grows and develops. The motor skills of most children with cerebral palsy improve as they grow, but the rate of improvement is slower in children with cerebral palsy than in unaffected children. The motor impairments result from various neurological deficits. CNS pathology associated with cerebral palsy includes: CNS haemorrhage; mechanical spinal-cord or brainstem damage; deep CNS hypoxia; cerebral cortex hypoxia; and transient or irreversible ischemia resulting in cell necrosis secondary to free-radical formation or hypoxia-related metabolic cellular death (**Schendel, 2001**). A specific hypoxic event associated with immediate and irreversible cell death explains the etiology of cerebral palsy in less than 50% of cases (**Nelson and Willoughby, 2000**). Furthermore, some areas of the brain are more susceptible to damage than others. For example, variations in blood supply and unique metabolic requirements in some brain areas increase the sensitivity to hypoxia in the presence of bacterial or viral infection of the fetus, fetal production of cytokines, or maternal infection or chorioamnionitis (**Gaudet and Smith, 2001**). "Selective vulnerability" of the periventricular white matter occurs between 26 weeks and 34 weeks of gestation, so fetal insults occurring during this period can produce periventricular