AN INVESTIGATION OF THE QUALITY OF LIFE IN CHILDREN WITH CEREBRAL PALSY

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MAY, 2015

CERTIFICATE

This is to certify that this dissertation entitled **"An Investigation of the Quality of Life in Children with Cerebral Palsy"** is a bonafide work submitted in part fulfillment for the Degree of Master of Science (Speech-Language Pathology) of the student (Registration No.: 13SLP029). This has been carried out under the guidance of a faculty of this institute and has not been submitted earlier to any of the University for the award of any Diploma or Degree.

Mysore
May 2015

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CERTIFICATE

This is to certify that this dissertation entitled "**An Investigation of the Quality of Life in Children with Cerebral Palsy"** has been prepared under my supervision and guidance. It is also certified that this has not been submitted earlier to any of the University for the award of any Diploma or Degree.

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DECLARATION

This is to certify that this dissertation entitled **"An Investigation of the Quality of Life in Children with Cerebral Palsy"** is the result of my own study under the guidance of Dr. Swapna. N., Reader in Speech Pathology, Department of Speech-Language Pathology, All India Institute of Speech and Hearing, Mysore, and has not been submitted earlier in other University for the award of any Diploma or Degree.

Mysore Register No.: 13SLP029
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DEDICATED TO

DAD & MOM

Thanks for the endless love and care

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Introduction

William Little was the first person to provide a medical description of a disorder in 1861, formerly named Little's disease, that caused stiffness and spasticity in the limbs of young affected children (Bax, Goldstein, Rosenbaum, Leviton, Paneth, Dan, Jacobsson & Damiano, 2005; Jones, Morgan, Shelton, & Thorogood, 2007; Shimony, Lawrence, Neil & Inder, 2008). A century later, Bax (1964) defined cerebral palsy (CP) as a disorder of posture and movement due to a defect or lesion of the immature brain. More recently Bax et al., (2005), through the American Academy for Cerebral Palsy and Developmental Medicine, proposed a new definition which describes CP as a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. They further stated that the motor disorders of CP are often accompanied by disturbance of sensation, cognition, communication, perception, and /or behaviour, and /or by a seizure disorder. CP has been identified as a permanent life long condition.

CP is said to be the most common cause of physical disability in children occurring in 2-2.5/1000 live births (Reddihough& Collins, 2003). It occurs early, usually within one year of age due to an abnormality of the brain resulting from prematurity, genetic disorders, infections of the brain, anoxia etc. The early signs which indicates CP are poor head control, delayed and abnormal motor development, abnormalities of muscle tone and reflexes, behaviour abnormality, problems in oromotor and disturbances in mobility. These children could also experience other associated problems such as epilepsy, hearing and visual problems, cognitive and attentional deficits, emotional and behavioural issues, feeding and swallowing problems, gastrointestinal, respiratory, musculoskeletal problems. Eight factors have also been recognized which can minimize the life span in children with CP. These include the number of impairments and key disabilities, severity level, mobility restrictions, feeding difficulties, seizures, cognitive functioning, visual acuity and respiratory functioning.

CP represents multiple handicaps due to which these individuals face numerous difficulties in their day to day life. These can lead to inadequacy in different areas such as self-care, speech, communication, learning, mobility, independent living and financial adequacy. Therefore, they need long-term care, treatment and rehabilitation. The severity of motor impairment and the associated cognitive communicative and behavioural impairments may differ for each child with CP. Because the level of severity differs, their abilities and level of participation in everyday activities may vary greatly (Rosenbaum, Paneth, Leviton, Goldstein & Bax, 2006). These children with severe degree of disability are usually entirely dependent for daily living and communication. These disabilities can in turn affect the individual’s quality of life.

Quality of life (QoL) is defined as the “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organization, 1997). QoL has also been explained in several other ways. Majnemer, Shevell, Law, Birnbaum, Chilingaryan, Rosenbaum, and Poulin (2008) defined QoL as the individual’s personal perspective of overall well-being and contentment in life, which includes both psychosocial and physical or health-related domains. This multidimensional construct (QoL) includes both health and non-health domains. Health-related quality of life (HRQoL) includes domains such as physical, mental/emotional and social well-being (Waters, Maher, Salmon, Reddihough, & Boyd, 2005). It assesses quality of life as affected by disease processes, conditions, and disorders. The more generalized wellbeing that takes into account factors other than health (such as finances, school, autonomy, support, spirituality, social and emotional wellness) is the non-health related QoL.

Several studies have been carried out to assess the HRQoL in children with CP using different questionnaires. The questionnaires used to assess HRQoL can be broadly divided into two types “Generic” and “condition specific”. Some of the studies have employed a generic questionnaire while other studies here used the condition specific questionnaire. For a broad range of health problems Generic QoL questionnaires are suitable for use. Some examples of these are Child Health Questionnaire (CHQ, McCarthy, Silberstein, Atkins, Harryman, Sponseller, & Hadley-Miller, 2002), KIDSCREEN (Ravens-Sieberer, Gosh, & Rajmil, et al., 2005) etc. The information related to a specific condition can be elicited using a condition specific QoL questionnaire, for e.g., Cerebral Palsy Quality of Life Questionnaire for Children (CPQoL-Child, Waters, Davis, & Boyd 2013), the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD, Narayanan, Fehlings, Weir, Knight, Kiran, & Campbell, 2006), the Pediatric Quality of Life Inventory (PDQoL, Varni, Burwinkle, Sherman, Hanna, Berrin, Malcarne, & Chambers, 2005) etc.

The condition specific questionnaires have their own advantages compared to the generic questionnaires. Condition specific QoL has been found to be useful in chronic conditions such as CP. The advantage of condition-specific instruments is that they are clinically relevant. These instruments do not contain any items or health dimensions that are not relevant to the disease. Furthermore, because the instrument has clear relevance to patients with the presenting problem, acceptability is likely to be high. However a potential disadvantage of these questionnaires is that it is not generally possible to administer condition-specific instruments to samples who do not have the relevant health problem. This means that health status scores cannot be compared with those for the general population, which is a common approach for assessing the impact of a particular condition on health status. It follows that it is not possible to make comparisons across treatments for different conditions, which limits the application of condition-specific instruments in economic evaluation.

Some of these questionnaires have been used to study even very young children with cerebral palsy. It is indeed a challenging task to measure HRQoL especially in those younger children. These children are often unable to communicate their perspective on quality of life. Under such circumstances, one is compelled to rely on the parents or caregivers to report their perception of their child’s quality of life. Such reports will no longer truly be a measure of the child’s HRQoL but a proxy that inevitably will be influenced by the parent’s or caregiver’s unique perceptions and attitudes, value judgments, as well as elements of their own quality of life. Nevertheless, such reports are the closest possible approximation of severely disabled children’s HRQoL and have generally proven to be reliable and valid (Sherifali & Pinelli, 2007; Varni, Limbers, & Burwinkle, 2007; Eiser & Jenney, 2007). This is consistent with real life practice, where health care providers ought to respond to the concerns of parents or caregivers and their perception of their children’s needs to arrive at recommendations that address these priorities.

There are several factors which influences the QoL of both children with CP and their families. These include environmental factors such as physical well- being, psychological well-being, moods and emotions, self-perceptions, autonomy, parental relations, social support and peers, school environment, social acceptance (bullying), financial resources, parents with higher levels of stress and depression, parents with high educational qualifications and single parent households. Other factors include the child’s level of disability, comorbidity and level of support. One of the main factors influencing HRQoL which is cited as the number one determinant in studies assessing the QoL is the “pain” experienced by people with CP. As shown, pain is not just present in children with severe CP, but present in children with mild severity as well. The current research indicates that pain is not well controlled in the adult population with CP, and it appears that this is true for the pediatric population as well (Bjornson, Belza, Kartin, Logsdon & McLaughlin, 2008). The children and parents believed that this was simply a part of life with CP which led to the inadequate treatment taken to combat pain (Bjornson et al., 2008; Dickinson, Parkinson, Ravens-Seiberer, Schirripa, Thyen, Arnaud, Beckung, Fauconnier, Mcmanus, Michelsen, Parkes, & Colver, 2007; Russo, Goodwin, Miller, Haan, Connell, & Crotty, 2008).

Davis, Shelly, Waters, Mackinnon, Reddihough, Boyd, and Graham (2009) identified the important facets and domains of QoL for adolescents with CP by using qualitative techniques. The fifteen themes identified by both adolescents with CP and their parents included physical health and physical changes, functioning, pain and discomfort, social well-being and acceptance, participation, independence and transitioning, emotional well-being and self-esteem, acceptance of disability, supportive physical environment including equipment, and getting on well at school. Other themes which were reported only by parents included communication, relationships and sexuality, access to services, parental health, and having adequate financial resources.

A cross sectional study was conducted by Liptak, Donnell, Conaway, Chumlea, Worley, and Henderson (2001) to evaluate the health and well-being in moderate to severe children with CP. Children between the ages 2-18 years and who had moderate to severe degree of impairment according to Gross Motor Function Classification System (GMFCS, Palisano, Rosenbaum, Walter, Russell, Wood & Galuppi, 1995, 1997) were included in the study. CHQ was used to interview all the caregivers. Results revealed that the study group scored significantly below the mean for all the categories of CHQ. The study also revealed that children with GMFCS level V who used a feeding tube and had the lowest estimate of mental age, required most health care resources, used most medications, had most respiratory problems and had lowest global health scores. The study also revealed that there was a relationship among different measures of health status such as the CHQ, functional abilities, use of resources, and mental age.

Another cross sectional study was conducted by Dickinson, Parkinson, Seiberer, and Schirripa (2007) to assess the self-reported QoL in 1174 children aged 8-12 years with CP selected randomly from 6 European countries. The KIDSCREEN instrument was used to assess the QoL which revealed that pain was common and this was associated with lower QoL on all domains. Bjornson, Belza, Kartin, Longsdon and Mclaughlin (2008) also showed that pain was experienced even by mild hemiplegic children with CP especially on the palsy affected side of their body. Impairments and pain explained up to 3% and 7% respectively, of variation in QoL. Children with CP had similar QoL to children in the general population in all domains except schooling, in which evidence was equivocal.

Arnaud, Koning, Michelsen, Parkes, Parkinson, Thyne, and Beckung (2008) conducted a study to determine whether the type and severity of the child's impairment and the family's psychosocial, social and economic characteristics influenced parent-reported child QoL. A cross sectional survey was conducted in Europe involved 818 children with CP, aged 8-12 years from Europe. KIDSCREEN questionnaire was used to assess parent reported child QoL. The results revealed that the parental response rates were high (93%–97%) for all domains except the financial domain (79%). Gross motor function and IQ level were independently associated, positively or negatively, with almost all domains, respectively. Children with severely impaired motor function were more likely to have poor QoL in the physical well-being and autonomy domains. Similarly, children with lower IQ were at higher risk of having a poor QoL in the social support domain. However, greater severity of impairment was not always associated with poorer QoL; in the moods and emotions, social acceptance, self-perception and school environment domains, less severely impaired children were more likely to have poor QoL. The risk of poor QoL in terms of social acceptance and school environment decreased with increasing severity of gross motor impairment. Similarly, children with an IQ of 50 were less likely to have poor QoL in the moods and emotions and self-perception domains than were other children. In the domains physical and psychological well-being and self-perception, pain was found to be associated with poor QoL. It was also found that parents with higher levels of stress were found to have poorer QoL in all domains which suggests that parent's report of the QoL may be influenced by the factors other than the severity of the child's impairment.

In the Indian context, a cross sectional study was conducted by Elizabeth (2010) to measure the self-reported QoL using CPQoL questionnaire, in 45 (19 males and 26 females) children with CP aged 9-13 years. The participants were recruited from the Rehabilitation unit of tertiary hospital in Karnataka and various rehabilitation centres for physically challenged in Kerala. They were divided into two groups, group 1 included children of the age range within 9-11 years and group 2 included children of the age range within 12-13 years. The results revealed that the domains such as social wellbeing, emotional wellbeing and functioning had the highest scores while the domain of pain, impact of disability, participation, and physical health had the lowest scores. Similar scores were obtained in both the genders. Children between 12 &13 years had reported scores that indicated poor QoL in comparison with the other group in all the domains.

Tella, Gbiri, Osho, and Ogunrinu (2011) assessed the impact of CP on QoL of Nigerian children. 54 children (33 males and 21 females) between 1 and 12 years of age with CP, participated in the study. Their QoL was assessed using the CHQ Parent Form-28 (McCarthy et al., 2002) which was completed by their parents, guardians or primary caregivers. The results indicated that CP had a negative impact on health status and QoL on children with CP as reported by the respondent parents. Children with CP had a reduced QoL, and the degree to which it was reduced was directly related to the age and severity of the CP.

A study was conducted by Abanto, Carvalho, Bonecker, Ortega, Ciamponi, and Raggio (2012) to assess the impact of impairments and oral health conditions in children with CP. 60 children, between 6-14 years of age were selected for the study. Oral Health-Related Quality of life (OHRQoL, Adu-Ababio, Ananaba, Johnson, & Peters, 2010) instrument which combines the Parental-Caregivers Perception questionnaire (P-CPQ) and Family Impact Scale (FIS) were answered by the parents. The results revealed that the severity of the type of CP, its reduction of communication ability and seizures showed a negative impact on oral symptoms and functional limitation domains. They concluded that the severity of dental carries, communication ability, and low family income were conditions strongly associated with a negative impact on OHRQoL of children with CP.

Sanna, Varho, Maenpaa, Forsten, Autti-ramo, and Haataja (2013) examined the QoL of Finnish children with CP, both from the child's and the caregiver's point of view, and analyzed the effect of background factors on QoL. The study employed CPQoL-Child. 128 questionnaires were sent to caregivers who had a 4 to 12 year-old child with CP. Children between 9 and 12 years were asked to fill in the child-self-report version which revealed that the overall QoL was reported to be good in Finnish children with CP. The correlation of QoL scores between the caregivers and children was good except in the domain of pain and the impact of disability.

A cross sectional study was conducted by Badia, Riquelme, Orgaz, Acevedo, Longo, and Montoya (2014) to explore the impact of pain on HRQoL and motor function in children with CP as reported by health professionals. 35 physiotherapists rated pain, HRQoL and motor functions in 91 children and adolescents with CP with a mean age of

12 years. Physiotherapists reported that 51% of children with CP suffered from pain and reported that pain in individuals with CP was responsible for reduction of psychological but not physical domains of HRQoL.

A study was conducted by Tessier, Hefner, and Newmeyer (2014) with the aim of assessing if there was an association between perceived psychosocial QoL of a child with CP with patient demographics, health status, including CP severity or comorbidity, and to determine if there was an association between the Family Centered Care (FCC) and psychosocial QoL for these children. A sample of 53 caregivers of children with CP aged 2-12 years was surveyed. The survey included a Measure of Processes of Care-20 (MPOC-20, King, Rosenbaum, & King, 1995) and the parent-proxy CPQoL-Child. GMFCS scale was used to classify the severity of illness. It was found that there was no significant association between age, sex or race and either psychosocial QoL domain viz., (social well-being and acceptance, emotional well-being and self-esteem) and no significant association was found between GMFCS level and psychosocial QoL. However comorbidity strongly correlated with both the domains of psychosocial QoL viz. social well-being and emotional well-being. Although higher FCC was associated with an increase in emotional well-being and self-esteem, in a multivariate linear regression model controlling for level of comorbidity, the FCC was no longer significantly associated with psychosocial QoL.

Another study was conducted by Dobhal, Juneja, Jain, Sairam, and Thaiagarajan (2014) to determine the HRQoL in Indian children with CP and their families in New Delhi in the age group of 3-10 years. Lifestyle Assessment Questionnaire (LAS, Mackie, Jessen, & Jarvis, 1998) was used to evaluate the impact of disability in children with CP and their families. The results revealed that 9% had good, 24% had mildly-affected, 37% had moderately-affected and 30% had severely-affected HRQoL. Lifestyle Assessment Score was significantly greater in boys when compared to girls indicating moderately affected QoL, and significantly more in subjects with quadriplegic CP indicating mildly affected QoL and seizure disorder, visual problems, cognitive deficits and feeding problems for which data was not shown. The physical independence, mobility and social integration dimensions were much more severely affected than the clinical burden, economic burden and schooling dimensions and they concluded that HRQoL is affected in most children with CP.

Need for the study

A look into the literature revealed that varied methods using different questionnaires have been employed to assess the HRQoL in children with CP in different countries across the globe. The domains of HRQoL studied are also different in different studies. The findings from these studies indicate that the relationship between the QoL of children with CP and their disability is not yet clear. This is because of the conflicting results obtained across studies. These studies have come to different conclusions regarding the impact of CP on the well-being of these children with respect to different domains assessed. Studies by Liptak et al., (2001); Arnaud et al., (2008); Elizabeth,(2010); Tella et al.,(2011); Abanto et al.,(2012); Badiya et al.,(2014); and Tessier et al., 2014 have reported that children with CP have poor HRQoL. However other studies by Bjornson et al.,(2007); and Sanna et al.,(2013); have reported that these children have good HRQoL. Certain studies by Bjornsonet al., (2007); and Arnaud et al., (2008) have reported that certain domains are only affected in children with CP revealing poor HRQoL. For example Bjornson et al., (2007) found that the QoL of these children was more influenced by social and environmental factors than by their disability and also reported that these children can report a good QoL in social and emotional domains (especially with strong family and friend support systems).

A look into the literature also reveals a growing interest in the assessment of HRQoL in children and adolescents with chronic health conditions as a subjective health outcome. However, HRQoL in the pediatric population with CP in comparison with other developmental disabilities, is still understudied, with scarce research assessing self-reported HRQoL and its links with other psychological variables. Such studies are essential because a study conducted in Turkey by Elbasan, Duzgun and Oskay in 2013 revealed that children with CP have the most affected QoL compared to other disabilities such as mental retardation and hearing impairment. This could be due to the fact that the children with CP were particularly more dependent than other disability groups. Moreover most children with CP have one or more associated problems such as mental retardation, seizures, hearing and visual impairment which may influence the overall HRQoL.

Further although studies have investigated the QoL, most of the studies have not associated it with variables such as type of CP and the topographical distribution. QoL could vary with whether the child is spastic or dyskinetic, quadriplegic or monoplegic. Very few studies have addressed the correlation between comorbidities and HRQoL (Abanto et al., 2012; Tessier et al., 2014; and Dobhal et al., 2014). Most of these studies have indicated a significant correlation between the two. Moreover the HRQoL can also vary with the age of the child. This has also been explored by a limited number of studies

(Elizabeth et al., 2010; Tella et al., 2011; Tessier et al., 2014) which have again yielded conflicting results. Further the extent of rehabilitation services received by the child with CP also can impact HRQoL. It would also be interesting to study whether HRQoL varied with gender especially in the Indian context where priority is given to provide all intervention facilities to boys especially in the rural population.

Further QoL needs to be measured since such studies provide guidelines for professionals in implementing effective rehabilitation programs to reduce the level of strain and increase the HRQoL, self- care and social function of children with CP. The measurement of HRQoL can help identify individual priorities that are problematic, so that therapeutic objectives, programs and policies may be aligned with needs of patients and caregivers (Schneider, Gurucharri, Gutierrez, & Gaebler-Spira, 2001, Von Steinbuechel, Richter, Morawetz, & Riemsma, 2005). This information might assist decision-making, and may be used in clinical practice to evaluate the patient's response to interventions that can guide on-going treatment or alteration in management (Dijkers, 1999). Consideration of HRQoL is therefore crucial in designing and maintaining a system of patient-centered care (Berzon, 1998). Since the goal of most interventions for these children is to preserve or improve QoL, these outcomes must be included in clinical trials of these interventions whenever possible. Keeping this in view, a need was felt to assess the QoL in children with CP.

Aim of the study: The present study aimed at assessing the QoL of children with CP in the age range of 4-12 years. The specific objectives of the study were:

Objectives of the study

- To compare the QoL scores obtained across different domains on the questionnaire in children with CP.
- To compare QoL across different severity of CP.
- To compare the QoL of children with CP with different topography
- To compare the QoL of children with CP across different age groups
- To compare the differences, in QoL, if any, across gender.
- To compare the effects of associated problems on QoL of children with CP
- To compare the influence of intervention on the QoL of children with CP

Chapter 2

Review of Literature

Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, balance and coordination causing activity limitation, that are attributed to non-progressive disturbances that occur in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy and by secondary musculoskeletal problems. Children with CP are representative of many disabled children as they have a range of physical, intellectual, vision, communication impairments, with a wide range of severity. The severity of the motor impairment and the associated cognitive communicative and behavioural impairments are different for each child with CP. CP can range from mild to severe and doesn't always cause profound disabilities. While one child with severe CP might be unable to walk and need extensive, lifelong care, another with mild CP might not require special assistance. With proper therapy, many children with CP can lead near-normal life. Even those with very severe disabilities can improve their condition significantly, although they will never be able to live independently. Because the level of severity differs, their level of participation in everyday activities will vary greatly (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2006).

Although CP is the most common motor disability in childhood, there is variation in the incidence reports of CP due to discrepancies among studies in terms of techniques used in survey and the population studied. Early studies estimated approximately 6 in every 1,000 live births in the United States to have CP (Mechan, Berko, & Berko, 1960).

With development of modern and advancing technologies in prenatal and perinatal care, as well as improved diagnostic procedures, there was a decline in the incidence of CP (Wellesley, Hockey, Montgomery, & Stanley, 1992). Age of the subject is one of the factor which clouds the incidence studies during the sample survey. An epidemiological study was conducted, in which extremely low birth weight survivors were followed at 1 year, 2 years, and 5 years of age (Atsbury, Orgill, Bajuk, & Yu, 1990). At age 5 fifty five of the infants who survived were found to have some type of disabling impairment. In the recent years the incidence of CP in the western countries is reported to be 2-2.5/1000 live births (Reddihough & Collins, 2003) and population-based studies from around the world report prevalence estimates of CP ranging from 1.5 to more than 4 per 1,000 live births or children of a defined age range. About 1 in 323 children has been identified with CP according to estimates from Centers for Disease Control and Prevention (CDC) Autism and Developmental Disabilities Monitoring (ADDM, 2008) Network. In India, National sample survey Organization (NSSO, 1991) records that CP is the cause for locomotor disability in 48% of the rural population and 43% of urban population. Vyas, Kori, and Rajagopala (2013)reported that the estimated incidence rate in India is around 3/1000 live births; however, being a developing country, the expected actual figure may be much higher.

Etiology of cerebral palsy

CP can be caused due to injuries to the brain at various stages from several weeks after conception (prenatal period), through birth (perinatal period), to early childhood (postnatal period). The major prenatal causes include insult during the first trimester as a result of maternal viral infection such as rubella, influenza, toxoplasmosis, cytomegalovirus, herpes, prenatal anoxia due to carbon monoxide, strangulation of mother, maternal anemia, hypotension following spinal anesthesia, placental infarcts or abruption placentae, knots or prolapse of the cord, prenatal cerebral haemorrhage due to maternal toxaemia, direct trauma, maternal bleeding, diathesis, metabolic disturbances, diabetes, gonadal irradiation, harmful exposure to X-ray, bleeding in the first semester etc. Other prenatal risk factors include effect of drugs, alcohol, tobacco, radiation, environmental pollutants and chemicals, malnutrition of placenta, maternal epilepsy, mental retardation, hyperthyroidism, third trimester bleeding and general health. Chorioamnionitis was found to be a risk factor for CP, in as many as 28% of premature infants. Cystic periventricular leukomalacia, a congenital brain malformation may also play a causative role (Denhoff & Robinault, 1960).

The major perinatal causes include complicacy of birth during labour and delivery, mechanical respiratory obstruction, narcotism (due to drugs), maternal anoxia or hypotension, breech deliveries with delay of the after-coming head, vaginal bleeding on admission, placental complications, trauma and haemorrhage due to dystocia, disproportions and malpositions, injudicious forceps application, holding back the head, pituitary-extract induction of labor, sudden pressure changes, precipitate delivery, prolonged labor, caesarean delivery, prematurity, kernicterus due to RH factor and other types of isoimmunisation, hyperbilirubinemia, syphilis, hemorrhagic disease of the new born, multiple pregnancies with significantly increased risk for CP. Twin pregnancies result in a child with CP about 12 times more than a single pregnancy, probably related to a low birth rate were all associated with increased rate of CP (Denhoff & Robinault, 1960).

Post-natal causes include trauma, subdural hematoma, skull fractures, wounds and contusions of the brain (accidental). Infections such as meningitis, encephalitis, brain abscess, toxic causes due to lead, arsenic, coal-tar derivatives, streptomycin etc., vascular accidents, congenital aneurysms, circle of Willis, hypertensive encephalopathies, emboli due to bacterial endocarditis or fat embolism, cerebrovascular thrombosis, sudden pressure changes in debilitated infants, anoxia due to carbon-monoxide poisoning, strangulation, high altitudes, deep-pressure anoxia, hypoglycaemia, neoplastic or late development defects as a result of brain tumors and brain cysts, There are also some causes which are genetically transmitted nervous system anomalies such as anencephaly, microcephaly and spina bifida (Denhoff & Robinault, 1960).

Clinical Manifestation

Impairments which results from CP range in severity and usually correlates with the degree of injury to the brain. Since CP is a group of conditions, signs and symptoms may vary from one individual to another. The primary effect includes the impairment of muscle tone, gross and fine motor functions, balance, control, coordination, reflexes, and posture. Oral motor dysfunction such as swallowing and feeding difficulties, speech impairment and poor facial muscle tone can also be seen in children with CP. Associative conditions such as sensory impairment, seizures, and learning disabilities that are not a result of the same brain injury, occur frequently with CP. When present, these associative conditions may contribute to a clinical diagnosis of CP. Depending on the location and extent of the damage to the brain the symptoms and effects may also vary.

Despite the great variation in symptoms, certain effects are common among people who have CP. Children with CP present with three types of motor problems:

primary, secondary and tertiary impairments. Primary impairment of muscle tone, balance, strength and selectivity are directly related to the damage in the central nervous system. Secondary impairments of muscle contractures and deformities develop over time in response to the primary problems and musculoskeletal growth. Tertiary impairments are adaptive mechanisms and coping responses that the child develops to adapt to the primary and secondary problems (Berker & Yalcin, 2010). Many signs and symptoms are not readily visible at birth, except in some severe cases, and may appear within the first three to five years of life as the brain and child develop. Following are the list of some of the signs and symptoms exhibited by children with CP:-

Primary impairment: CP affects the areas of the brain that control muscle tone, movement, balance and coordination. As a result, all individuals who have CP experience some degree of difficulty making smooth, deliberate movements. Typical symptoms include:

- Abnormal muscle tone (muscles with too much or too little tone).
- Muscles that pull unevenly on the joints.
- Delayed development of motor milestones.
- Abnormal or pathological reflexes.
- Presence of stiffness and spasms in muscles.
- Balance and coordination problems
- Development of handedness before 18 months of age which could indicate an inability to use the other hand appropriately.
- Preference to use one side of the body
- Feeding or swallowing difficulties.

- Difficulties with hearing, vision and speech as well as bladder and bowel problems.

Secondary impairment: As the child grows and develops, the primary effects of CP can lead to secondary effects, including:

- Inadequate muscle growth, which causes contractures (shortening) of muscles and tendons
- Bone deformities
- Misalignment of the joints
- Excessive fatigue with movement and walking
- Pain

Tertiary impairment: The primary and secondary effects of cerebral palsy can lead individuals to adopt "coping responses"—ways of moving that compensate for challenges. For example, abnormal muscle tone in the legs can result in stiff knees that can make walking difficult. People might compensate for this challenge by swinging their legs in a circle rather than a straight line when walking.

Associated Problems in Cerebral Palsy

There are many problems other than the motor dysfunction in a cerebral palsied individual. Some of these problems are the direct consequences of the brain pathology that also cause the basic motor dysfunction and some are the results of abnormal sequence of events which accompany the neuromuscular problems. These problems have been briefed below from Berker and Yalcin (2010).

- **Intellectual impairment:** Cognition refers to specific aspects of higher cortical function; namely, attention, memory, problem solving and language. Cognitive disturbance leads to mental retardation and learning disability. The prevalence of moderate, severe and profound mental retardation is 30 to 65% in all cases of CP. This is most common in spastic quadriplegia.

- **Epileptic seizures:** Seizures affect about 30 to 50% of the individuals with CP. They are most common in hemiplegics, in patients with mental retardation and in post natally acquired CP. Seizures most resistant to drug therapy occur in hemiplegics. Seizure frequency increases in the preschool period.
- **Vision problems:** Approximately 40% of all individuals with CP have some abnormality of vision or occulomotor control. If there is damage to the visual cortex, the child will be functionally blind because he/she will be unable to interpret impulses from the retinas. In severe cases, the optic nerves may also be damaged. Loss of coordination of the muscles controlling eye movements is very common. The child cannot fix his gaze on an object. In half of the cases, binocular vision does not develop. Myopia is a concomitant problem.
- **Hearing:** Sensorineural hearing loss is seen in 10 % of children. Children born prematurely are at high risk for hearing loss. It is generally not diagnosed early because of other handicaps. This is most commonly seen in athetoid type of CP.
- **Communication problems and dysarthria:** The children have difficulty producing sounds and dysarthria occurs in 40% of the individuals with CP. The causes are respiratory difficulties due to respiratory muscle involvement, phonation difficulties due to laryngeal involvement, and articulation difficulty due to oromotor dysfunction. Spasticity or athetosis of the muscles of the tongue, mouth and larynx causes dysarthria.

- **Oral nutritional problems:** Oral feeding control is a problem in most moderate to severely impaired children with CP. Because of their poor oral control, food intake becomes a problem and more food is wasted (they push out or spit out) than they could chew and swallow. Hence malnutrition is a frequently observed problem.
- **Gastrointestinal problems:** Some children with CP may exhibit gastroesophageal reflux disease (GERD) and may present with feeding difficulties, recurrent vomiting and recurrent chest infection associated with poor growth and nutrition, reactive airway disease particularly nocturnal asthma, choking attacks, anemia and wheezing. Onset of symptoms of GERD occur relatively late in neuro developmentally retarded children in comparison to children of normal development.
- **Respiratory problems**: Aspiration in small quantities leads to pneumonia in children who have difficulty swallowing. Premature babies have bronchopulmonary dysplasia. This leads to frequent upper respiratory tract infections. Respiratory muscle spasticity contributes to the pulmonary problems.
- **Bladder and bowel dysfunction**: Loss of coordination of bowel and bladder sphincters results in constipation and/or incontinence. Enuresis, frequency, urgency, urinary tract infections and incontinence are common problems. The causes are poor cognition, decreased mobility, poor communication and neurogenic dysfunction. Urodynamic assessment has demonstrated bladder hyper reflexia, detrusor sphincter dyssynergia, hypertonic bladders with incomplete leakage and periodic relaxation of the distal sphincter during filling. Constipation

is a common but overlooked phenomenon. It causes distress in the child, increases spasticity and results in poor appetite. It is a result of many factors, including poor diet and decreased mobility.

- **Psychosocial problems**: A diagnosis of CP is extremely stressful for the family and the child when he grows up. This causes various reactions ranging from denial to anger, guilt and depression. Coping with the emotional burden of disability is easier if the family has strong relationships, financial security, and supportive members of the community. The child and the family need to find ways to connect to each other. A healthy relationship between the mother and the child forms the basis of future happiness.
- **Psychological and behavioural problems:** These can also be identified as being direct consequences of brain pathology or acquired psychological deficits due to the pathology itself. These sensory perceptual deficits and intellectual retardation fall into the former category whereas the behavioural problems like hyperactivity and distractibility fall into the latter type.

Types of cerebral palsy

Although different CP classification systems exist today to define the type and form of CP an individual has, which includes the site of lesion, effects on movement and the identification of affected extremities, it is difficult to classify the various types of CP since motor ability and coordination vary greatly in these children (Miller & Bachrach, 1995). **A few of the popular classification systems are listed below (Berry & Eisenson, 1956).**

I. Based on neuromuscular symptoms, CP can be classified into the following ways:-

1. Spastic cerebral palsy: Spasticity is caused by damage or injury to the part of the central nervous system (the brain or spinal cord) that controls voluntary movement. This damage disrupts important signals between the nervous system and muscles, creating an imbalance that increases muscle activity or spasms. Spasticity can make one's movement, posture, and balance difficult. It may affect the ability to move one or more of your limbs, or to move one side of your body. Sometimes spasticity is so severe that it gets in the way of daily activities, sleep patterns, and caregiving. In certain situations, this loss of control can be dangerous for the individual. In this type of CP there is excessive contraction and tight muscles, usually brought about by hypersensitive stretch reflexes. There is an increased muscle tone and exaggerated stretch which interfere with normal movement (Batshaw & Perret, 1981).

In early months the infants with spasticity lie quietly without trying to use the affected limbs and when he/she cries or attempts to reach or sit, movements are jerky and explosive. Usually the baby lies with the arms flexed and legs extended, while the thighs are held in an adducted position. With further growth there is a tendency toward scissoring. Ankle equinus and internal rotation of the hips are frequent associated findings, and the hips and knees are held rigidly when the infant is supported for standing. Depending upon the degree of severity of the involvement, periods of hyper tonicity may be noted in the mildly or moderately handicapped infant. While in severely damaged baby the mass movement in all the extremities are flexed or extended simultaneously. In milder cases there may be difficulty in recognizing spasticity except that when the child walks, he occasionally toe-walks or has a wide based gait. Frequently demonstrates a peculiar specific pronation (deformity of the hand) when the spastic limb is used. Strabismus and drooling are not uncommon, while convulsions, mental retardation and hyperactive, destructive and distractible behaviour are found increasingly during the early years. In severe cases the movements of the child are slow and laboured and walking becomes jerky and unrhythmic. Balance is faulty because of poor weight distribution and contractures. The incidence of mental retardation and convulsions is highest in spasticity. Spastic CP occurs when there is damage to the pyramidal system of the brain. It is the term used to describe muscle tone that is hypertonic. It is the most common form of CP, as it occurs in 70-80 percent of all cases (Pellegrino & Dormans, 1998).

2. Rigidity: This condition occurs due to a lesion in the extrapyramidal system and is considered as extreme form of spasticity. It is characterized by equal involvement of agonist and antagonist muscles. If the resistance to passive motion is continuous, it is referred to as the “lead-pipe” rigidity; if discontinuous it is referred to as “cog-wheel” rigidity. The resistance is greater to slow than to rapid motion, whereas, in spasticity, there is greater resistance to rapid motion. In rigidity, the antagonists to the antigravity muscles are most involved. Total motion may be decreased. The main characteristic is hyper tonicity, normal or diminished reflexes, no clonus, no stretch reflexes and no involuntary motion.

3. Atonic cerebral palsy: This condition occurs due to a lesion in the lower motor neuron/peripheral nerves characterized by lack of tone, and failure of muscles to respond to volitional stimulation. The muscle lacks the firmness or turgor of the normal relaxed muscle. Weak stretch reflex may be obtained as well as increased deep reflexes, but no involuntary motion is present. This distinguishes it from non-tension athetosis (just a matter of degree). This is rare in pure form, but may be the initial symptom in any of the forms of cerebral palsy. It deserves special mention because it may be the outstanding initial symptom. The atonic form of cerebral palsy, in most instances, does not describe a type, but the outstanding symptoms of a type.

4. Ataxic cerebral palsy: Ataxic CP is caused by damage to the cerebellum and affects the coordination. Ataxia is primary incoordination due to disturbance of kinesthetic or balance sense, or both. Characterized by disturbance in the sense of balance and equilibrium, dyssynergias, and the patient often exhibits the “rebound phenomenon” with astereognosis and depth perception involvement. The muscles of the body are often hypotonic or flaccid. This does not produce involuntary movements, but instead indicates impaired balance and coordination. Walking gait is often very wide and sometimes irregular accompanied by difficulty judging the direction, extent, and accuracy of movement. Control of eye movements and depth perception can be impaired. Often, fine motor skills requiring coordination of the eyes and hands, such as writing, are difficult. The child with ataxic CP may also suffer from intension tremor which begins with the voluntary movement. For example when a child with CP tries to reach for a toy his arms and hands start to shake. It is characterized by hypotonia and affects 5-10 percent of the CP population. Persons with ataxia present with unsteady or shaky movement or tremors. They typically experience balance and coordination problems, which negatively affect ambulation, writing, and dressing.

5. Athetoid cerebral palsy: Athetoid CP is the result of damage to the extrapyramidal system. It results in mixed (sometimes hypertonic and sometimes hypotonic) muscle tone and impairs the person’s ability to control involuntary movements. It affects 5-10 percent of persons with CP and is the least common type. It is characterized by slow, writhing, involuntary movements; these movements progress from central to distal areas of the body in a wave like motion. These uncontrolled movements make it difficult for the person to grasp objects and to coordinate muscles for ambulation. During the early years arm and leg movements are purposeless in athetosis, compared to the purposeful repetitious motions of normal infants. Use of the arms will frequently initiate extraneous movements of the trunk and legs as well. Tension in the form of intermittent stiffening spells or extensor spasms, when the child reaches for object or for balance, becomes more apparent with growth. Straightening of the arms with clenching of the fists is characteristic. Such children differ from spastics in that their arms are often drawn back or the forearms held with palms downward, the fingers overextended and spreading outward in almost constant activity when not at rest. The feet may turn inward and the toes tend to be held upward in the Babinski position. In severe cases, the movements may appear similar to a non-swimmer flailing around in the water. May involve any combinations of limbs. The arms are usually affected more severely than the legs in quadriplegics. A child with athetoid CP walks in a writhing, lurching and stumbling manner with a good deal of overflow of the arms when he moves. This overflow is variable and if the child is confident and not fearful at the moment, or if he is well rested, he may walk surprisingly well. Anxiety and fearfulness are part of picture with these children and may increase the effects of physical impairment more than is expected. The head may be held back, neck thickened and bull like, muscles of the face and tongue can also be affected, face may be masklike resulting in grimaces, odd facial expressions or drooling.

6. Dystonic cerebral palsy: This type of CP occurs due to lesion in the extrapyramidal system and is considered as a extreme form of athetosis. This is characterized by involuntary movements accompanied by an abnormal, sustained posture. The extremities assume distorted positions held involuntarily for periods from a few seconds to a few minutes. The dystonic motions may involve neck, trunk, arms, and legs. The trunk muscles are affected more than the limbs and results in fixed, twisted posture.

7. Tremor: This type of CP occurs due to a lesion in the extrapyramidal system and exhibits uncontrollable, involuntary motions of a rhythmic, alternating or pendular pattern due to alternate agonist and antagonist contractions often referred to as a trembling or shaking motion. The movement is of smaller amplitude and is more rapid and rhythmic than the movements seen in athetosis. The movements may be intentional, non-intentional or constant. Intentional tremor occurs primarily when the person initiates volitional movement but is not noticeable when the muscles are at rest. Nonintentional tremor occurs when the person is at rest but often disappears when volitional movement occurs.

8. Ballismus: This type results from lesion in the subthalamic nucleus. It is characterized by involuntary, rapid, violent, flailing movements of the extremities. If the lesion is associated with the contralateral side, then it results in a condition called hemiballismus. This type is also associated with dyskinesia and other types of CP.

9. Myoclonus: This type of CP occurs due to lesion in the extrapyramidal system. In this type involuntary movements occurs due to rapid, abrupt, twitching unsustained muscle contractions in large and small groups of muscles. There are two types of myoclonus seen

a) Synchronous myoclonus: in which a number of muscle groups jerk or contract at the same time or one after the other b) Asynchronous myoclonus: in which a number of muscle groups contract at different times. The muscles of facial structures may also be involved which could result in involuntary movements in the palatal, laryngeal and pharyngeal regions which could affect speech. This type may also be associated with convulsive disorders.

10. Chorea: This occurs due to lesion in the extrapyramidal system which results in involuntary movements that are not repetitive or rhythmic, and tend to be more jerky and shaky which are described as quasi purposive. That is these movements resemble movements of a high order (although they achieve no purpose). They resemble fragments of purposive movements following one another in a disorderly fashion e.g., the eyes may be rolled from one side to another, the head turning in the same direction etc. The tone fluctuates between hyper and hypotone.

11. Mixed cerebral palsy: This type occurs due to injury to both extrapyramidal and pyramidal areas to the brain. Children with mixed type exhibit combination of neuromuscular characteristics. The mixed class is not used often, as the predominant motor symptoms determine the classification.

II.CP can be classified on the basis of topography i.e. according to the number and location of limbs involved.

A. Monoplegia: Involves one limb and this condition is rare.

B. Paraplegia: Involves the legs only and practically always of the spastic or rigidity type.

C. Hemiplegia: The lateralized one-half of the body is affected and it is usually spastic, although pure athetoid hemiplegias are occasionally seen, as are pure rigidity hemiplegias. There is often sensory involvement in the areas of proprioception to point discrimination and form perception. Aphasias appear more frequently in right than in left hemiplegias and are much more common in the acquired than in the congenital cerebral palsy.

D. Triplegia: Involves three extremities, usually both legs and one arm, usually spastic. This may represent hemiplegia plus paraplegia, or incomplete quadriplegia. In the latter case, both arms will be equal or nearly equal in length. In the former, the involved arm will be shorter.

E. Quadriplegia: Involvement of all four extremities. Patients with the greatest involvement of the legs are usually spastic, and patients with greatest involvement of the arms are usually the dyskinetics, including athetoids. Thirty percent of children with spastic CP have quadriplegia.

F. Diplegia: This term is seldom used. It is the paralysis affecting like parts on either side of the body. The lower extremities are severely involved and the arms are mildly involved. Fifty percent of the children with spastic CP have diplegia.

C. Double Hemiplegia: This term implies for those cases in which the arms are more involved than the legs. These are usually spastic in type (William & George, 1955).

Management of Children with Cerebral Palsy

There are many impairments seen in children with CP in aspects of sensation, perception, cognition, communication and behaviour. Epilepsy, difficulties with sleeping, drooling and feeding are other problems seen in children with CP and therefore in children with CP rehabilitation involves a long term process involving intensive and systematic management from various professionals who must work effectively with the family as a team. Priorities in management includes the education of family, addressing infant's specific needs, providing support for adequate growth and development, attending to play activities, education for mainstreaming and peer socialization. These play an important role in the development of the child with CP (Bleck, 1987). Priorities in the management include:

Communication: To express feelings, thoughts and needs and to be a part of the community and family communication is necessary. The speech and language therapist is primarily concerned with a child's communication. Since communication functions as both the ability to understand and the ability to communicate with the outside world, a speech and language therapist will focus equal attention on both facets of a child's communicative ability. They are concerned with establishing how a child understands language, whether he or she can understand verbal instructions or whether he or she needs clues from his or her environment to understand what is going on around them. The communication is enhanced through activities that encourage speech, signing, electronic aids or even a picture board. It has been noted that children who communicate with more than one method, such as a child who signs while they are speaking, are more likely to increase their vocal communication development. Children with even the mildest case of CP often tend to be slow in developing verbal communication. Even if a child with CP is able to speak well, a speech and language therapist can assist them by helping to make speech clearer and easier to understand, or on building their language skills by expanding their vocabulary, learning to speak in sentences, or improving their listening skills.

In addition speech and language therapists frequently help the child and his or her family to establish normal feeding patterns, as there is much research that suggests a correlation between good feeding patterns and the eventual possibility of developing normal speech. The correlation exists because the muscles used for feeding are the same muscles for speaking, and early development of these muscles in children with CP has shown to improve the functions employed by these muscles.

Mobility: To improve cognitive abilities children need to explore their surroundings since mobilization is crucial for young children with CP to prevent deprivation of secondary mental abilities. To improve the mobility, physiotherapy is required which involves exercises, bracing etc. It aims in bringing the child in erect position, bringing independent mobility and prevention of deformity. Use of wheel chair and other assistive mechanical devices can promote mobility in children who cannot achieve mobility by walking through physiotherapy.

Activities of daily living: Children with CP have difficulty with dexterity and fine motor movements that prevents their independence in daily activities such as feeding, toileting, bathing, dressing etc. These children sometimes require help from the occupational therapist.

Psychosocial issues: Children receiving intensive physiotherapy and surgery without any gains develop psychological problems in adolescence and adulthood. Lack of the independent mobility and presence of deformity even after prolonged years of therapy increases frustration, anxiety, depression which decreases independence further. In addition they may have behaviour problems and hence will require the intervention by a clinical psychologist.

In addition other medical professionals such as paediatrician, neurologist and orthopaedic surgeon are also involved in treating individuals with CP. Neurologist plays an important role in treating individuals with cerebral palsy who have convulsions. In individuals with severe contractures orthopaedic surgeon play an important role to help in improving the ability to walk and move by strengthening the muscles which are affected, correcting their arms, legs and curvature of spine (scoliosis).

Quality of Life in Children with Cerebral Palsy

CP represents multiple handicaps due to which these individuals face numerous difficulties in their day to day life. These can lead to inadequacy in different areas such as self-care, speech, communication, learning, mobility, independent living and financial adequacy. Moreover the severity of motor impairment and the associated cognitive communicative and behavioural impairments are different for each child with CP. Therefore, some of them need long-term care, treatment and rehabilitation and are usually entirely dependent for daily living and communication. Because the level of severity differs, their level of participation in everyday activities will vary greatly (Rosenbaum, Paneth, Leviton, Goldstein & Bax, 2006).These disabilities can limit the individual’s activities and participation and can cause a decrease in the quality of life (QoL). The higher the disability level of the child and more severe presence of motor deficits, the higher is the reduction in the child's overall QoL (Elbasan, Duzgun & Oskay, 2013).

CP can range from mild to severe and doesn't always cause profound disabilities. While one child with severe CP might be unable to walk and need extensive, lifelong care, another with mild CP might not require special assistance. With proper therapy, many children with CP can lead near-normal life. Even those with very severe disabilities can improve their condition significantly, although they will never be able to live independently.

Quality of life (QoL) is defined as the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHO, 1997). Several other definitions were also put forth by other researchers. Bjornson and McLaughlin (2001) defined QoL as an overall assessment of well-being across various domains explained in many ways. According to Majnemer, Shevell, Law, Poulin, and Rosenbaum (2008), QoL is the individual's personal perspective of overall well-being and contentment in life, which includes both psychosocial and physical or health-related domains. This multidimensional construct (QoL) includes both health and non-health domains. Health-related quality of life (HRQoL) is a subdomain of the more global construct of QoL which includes domains such as physical, mental/emotional and social well-being (Waters, Maher, Salmon, Reddihough, & Boyd, 2005). It assesses quality of life as affected by disease processes, conditions, and disorders. The non-health related QoL includes an overall, more encompassing and generalized well-being that takes into account factors other than health (such as finances, school, autonomy, support, spirituality, social and emotional wellness).

Elbasan, Duzgun, and Oskay (2013) studied the differences in HRQoL in children with different disabilities, in terms of their self-care and social function in their daily life activities. Three groups with different disabilities composing of one hundred and two children with physical, emotional and cognitive disabilities (cerebral palsy, mental retardation, and hearing loss) and 28 children age matched as a control group were included in this study for the comparison. The Pediatric Evaluation of Disability Inventory (PEDI, Haley, Coster, Ludlow, Haltiwanger & Andrellos, 1992) was used to evaluate the independence and participation of children in daily life activities. The Turkish version of the Child Health Questionnaire-Parent form (CHQ - PF50 Landgraf, 2001) was used to evaluate the HRQoL. The findings revealed that all the three groups were different from the control group in terms of self-care and the social domains. The children with CP were more dependent in the areas of self-care and mobility activities. It was concluded that all the children with disabilities were different from the control group, however the status of the children with mental retardation and hearing loss paralleled between each other in their QoL, self-care and social function. On the other hand, the most affected and dependent group was children with CP.

Factors Affecting QoL

There are several factors which influences the QoL of both children with CP and their families. These include environmental factors such as physical well-being, psychological well-being, moods and emotions, self-perceptions, autonomy, parental relations, social support and peers, school environment, social acceptance (bullying), financial resources, parents with higher levels of stress and depression, parents with high educational qualifications and single parent households. Other factors include the child’s level of disability, comorbidity and level of support.

In addition pain in children with CP has a high prevalence and has an impact on their QoL (Schneider & Majnemer, 2013). Literature reveals that pain is considered the number one determinant of QoL and children experiencing pain reported lower QoL in several domains. Pain can affect every part of the body and interfere with sleep in children with CP. Depending on a child’s condition, secondary issues can be a significant cause of pain. For instance, if a child uses a wheelchair for a significant amount of time per day, the act of sitting in the chair can be painful. But most often, pain will be dependent on the type of CP a child has, and the severity of his or her condition. The most common causes of pain that a child may suffer from include spasticity, motor dysfunction, joint dysfunction, scoliosis, hip subluxation, respiratory problems, intestinal problems, esophagitis, urinary tract infections, nerve injuries, osteoarthritis, spinal and back pain. The reasons these conditions cause pain are complex. Spasticity, the most common form of CP, causes pain because it causes functional problems that can lead to contractures and cartilage degeneration. Also, spasticity is linked to a chronic shortening and misalignment of muscles that require surgical and non-surgical interventions to correct. This is, in addition to pain caused, by muscle spasms and tremors. Orthopedic conditions are also a significant source of pain. Range of motion and immobility conditions are the primary source of pain. Children who have problems that cause them to be immobile suffer from several symptoms that, if not addressed, can cause pain. Often, these conditions cause a child to undergo one or more orthopedic surgeries.

In a study on children with mild hemiplegic CP researchers found that almost half of the children interviewed (out of 107 children with an average age of 9 years old) experienced a chronic, aching pain, usually on the palsy-affected side of their body. As shown, pain is not just present in children with severe CP, but in children with mild CP as well (Bjornson, Belza, Kartin, Logsdon, & McLaughlin, 2008). Since children with CP experience more pain and discomfort, if early rehabilitation is provided, the pain can be kept under control resulting in increased QoL (Elbasan et al., 2013).

In addition to pain, studies have been carried out to assess the influence of parenting style on QoL. A study was conducted by Aran, Biran, and Shalev (2007) to assess the impact of parenting style on the QoL of children with CP and their siblings. A total of thirty-nine children with CP, their siblings, and their parents participated in the study. Probands and siblings between the ages 6-18 years, completed a questionnaire on parenting style (accepting, rejecting, controlling, and autonomy) using the Children's Report of Parental Behaviour Inventory (CRPBI, Schaefer, 1965). Parents had completed generic CHQ and disease-specific Pediatric Outcomes Data Collecting Instrument (PODCI), for both groups of children. Disease severity was determined using the GMFCS. The results revealed that the parental report on health of children with CP was poorer for every subscale of the CHQ. The physical summary score and the psychosocial summary score were more than 2 SD lower than that of their healthy siblings. Scores in all the physical scales of the CHQ were markedly lower for children with severe CP compared to those for children with moderate and mild CP. Responses to the PODCI questionnaire, which taps the ability to function in activities of daily life, were similar. For siblings, there was no correlation between parents' CHQ scores and the level of disability of their sibling with CP. It was concluded that parenting style was a most important factor affecting the psychosocial aspects of QoL of children with CP. The impact of parenting style on psychosocial aspects of QoL was far greater than other factors assessed in this study, including severity of illness, IQ, socioeconomic status, and anxiety level.

A study was conducted by Chen, Tseng, Sheih, and Huang (2014)to identify the determinants of QoL of children with CP. A total of 167 children with CP aged between 4 and 12 years and their caregivers participated in the study. The Chinese version of the CPQoL-primary caregiver proxy report form questionnaire was used as a measure to assess QoL in children with CP. Based on all International Classification of Functioning (ICF) dimensions the potential determinants of QoL were collected. Results revealed that in children with CP, Children’s behavioural and emotional problems as well as caregiver’s psychological and family related factors were the important determinants of QoL.

Some studies also point towards the influence of parental stress while rating the questions of the QoL questionnaire. For e.g., Arnaud, Koning, Michelsen, Parkes, Parkinson, Thyne, and Beckung (2008) found that parents with higher levels of stress were found to have poorer QoL in all domains which suggests that parent’s report of the QoL may be influenced by the factors other than the severity of the child’s impairment. Similarly a study was carried out by Koning, Grandjean, Colver, and Arnaud (2008)to compare the reports of parents and professionals of the QoL of 8 to 12-year-old children with CP and associated intellectual impairment from several countries in Europe and also to determine the factors associated with low child QoL according to the parents and professionals. Professional (teacher, therapist, or residential carer) and parent reports of QoL for 204 children (127 males, 77 females with CP were obtained in nine European regions, using the KIDSCREEN questionnaire. GMFCS was used to classify the motor function and two items from the Child Health Questionnaire was used to assess pain by the parents and professionals. Parenting Stress Index ⁄Short form was used to assess the parental stress. It was found that high parental stress was significantly associated with low parent-reported child QoL in all the domains. In the professional proxy-reports, the severity of the child's physical impairment was associated with lower child QoL in the physical, autonomy and psychological domains.

Assessment of Quality of Life

There are many tools which have been developed for assessing QoL. There are generic, condition specific, and age specific questionnaires available. Some of the studies carried out to assess QoL in children with CP have employed a generic questionnaire while other studies have used the condition specific questionnaire. For a broad range of health problems Generic QoL questionnaires are suitable for use. Some examples of these are Child Health Questionnaire (CHQ, McCarthy, Silberstein, Atkins, Harryman, Sponseller, & Hadley-Miller, 2002), KIDSCREEN (Ravens-Sieberer et al., 2005) etc. The information related to a specific condition can be elicited using a condition specific quality of life questionnaire for e.g., Cerebral Palsy Quality of Life Questionnaire for Children (CPQoL, Waters et al., 2007), the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD, Narayanan, Fehlings, Weir, Knight, Kiran, & Campbell, 2006), the Pediatric Quality of Life Inventory (PDQoL, Varni, Burwinkle, Sherman, Hanna, Berrin, Malcarne, & Chambers, 2005) etc.

The condition and age specific questionnaires which have been developed as general versions have failed to question areas of life relevant to specific populations in an appropriate manner (Davis, 2010). For example, for individuals with CP, part of assessing the physical domain of quality of life is querying their feelings about their ability to perform daily tasks, which may be affected by hemiplegia, quadriplegia or ataxia. Questioning more specifically would be of greater relevance to the individual and would lead to reliable results (Davis, 2010). Tools of assessment which have been more recently developed and validated have given the opportunity to explore QoL in children with specific disabilities such as CP (Rosenbaum, Livingston, Palisano, Galuppi, & Russell, 2007).

Vargus-Adams and Martin (2009) carried out a study to assess the domains of importance in therapeutic intervention for CP using categories of the International Classification of Functioning, Disability, and Health - Version for Children & Youth (ICF-CY) domains from the perspectives of youth with CP, their parents and health professionals and the best tools for evaluating these domains from the perspectives of youth with CP, their parents and health professionals. They used five surveys to explore these topics and found eight domains of importance. These were impairment, general health, self-care/fine motor skills, integration/participation, quality of life, gross motor skills, speech/communication and caregiver issues (Vargus-Adams & Martin, 2009).

Davis, Shelly, and Waters (2009) identified the important facets and domains of QoL for adolescents with CP by using qualitative techniques. The fifteen themes identified by both adolescents with CP and their parents included physical health and physical changes, functioning, pain and discomfort, social well-being and acceptance, participation, independence and transitioning, emotional well-being and self-esteem, acceptance of disability, supportive physical environment including equipment, and getting on well at school. Other themes which were identified only by parents were communication, relationships and sexuality, access to services, parental health, and having adequate financial resources. According to GMFCS level there was no variation in themes. Of these domains, quality of life was found to be the most important.

On review of available tools for assessing QoL, there were four identified as being relevant to children with CP. These were KIDSCREEN, Quality of Life Questionnaire for Children with Cerebral Palsy, Pediatric Quality of Life Inventory (PDQoL, Varni, Burwinkle, Sherman, Hanna, Berrin, Malcarne, & Chambers, 2005) and CPCHILD. Of these the CPQOL-Child was perceived as the most appropriate in the present research for assessing QoL as it is a condition-specific questionnaire. In addition it also has a strong basis in qualitative research (Vargus-Adams & Martin, 2009).

The CPQoL-Child questionnaire has been developed to be used as a condition-specific tool of assessment. In the initial stages, qualitative interviews with both parents and children were used to establish what comprised QoL from their perspectives (Waters, Maher, Salmon, Reddihough, & Boyd, 2005). This questionnaire includes seven domains viz. Family and Friends, Participation, Communication, Health, Special equipment, Pain and Bother and Access to services. There are two versions available: parent proxy and self-report version. The parent-proxy version in which the parents report on the QoL of the child, was validated for an age range of 4-12 years old (Davis, 2010). The self-report version was for children aged 9-12 years in which information from the child perspective was considered beneficial due to QoL being largely an individual’s perception of their own state (Waters, 2009). Therefore, the use of both versions was recommended to be preferable if possible for a greater depth of information. There has been one direct validation study done with the CPQoL-Child, comparing it with two other well used and validated tools; the Child Health Questionnaire (CHQ) and a generic QoL questionnaire KIDSCREEN-10 (Davis, et al., 2010). The CPQoL-Child was found to be as valid and internally consistent as KIDSCREEN and performed more strongly than CHQ (Davis, Shelly, Waters, & Davern, 2010).

A study was conducted by Parkinson, Rice, and Young (2011) to investigate the views between children with CP and their parents that contributes to the children's QoL. Children from UK with CP aged 8 to 13 years and their parents participated in qualitative interviews about their perspectives on the child's QoL. It was revealed that interview with the children and parents showed considerable overlap but also some divergence where both the parties considered social relationships to be important, but children described how they enjoyed being on their own at times where as parents tended not to value time spent alone for children. The CPQoL-Child covered most themes considered to be important to the children's QoL. It was concluded that both children's and parents' views are required for the development of child health- related QoL instruments.

Quality of Life in Children with Cerebral Palsy

Several studies were carried out to assess QoL in children and adolescents with CP using different condition specific HRQoL questionnaire. Some of these studies have been described below.

A cross sectional study was conducted by Liptak, Donnell, Conaway, Chumlea, Worley, and Henderson (2001) to evaluate the health and well-being in moderate to severe children with CP and to explore the relations between health and function to enhance understanding of the underlying concepts of general health and well-being among this group of children and their families. Children clinically diagnosed as CP between the ages 2-18 years and who had moderate to severe degree of impairment according to GMFCS levels III, IV and V were included in the study. A detailed anthropometric assessment was performed by a trained observer using standardized techniques which included measures such as weight, head circumference, upper arm length, knee height, calf circumference, mid arm circumference, triceps and subscapular skinfold thickness. These measures were carried out twice and average of these were used for analysis. CHQ was used to interview all the caregivers which consisted of different questions developed specifically for this study and categories measured under this were global health, physical functioning, behaviour, mental health and impact on parents. According to GMFCS 56 children were classified under level III, 55 in level IV, 122 in level V (most severe), and 59 children used feeding tubes. Results revealed that study group scored significantly below the mean for all the categories of CHQ and according to National sample these children used more medications than children without CP. The results also revealed that children with GMFCS level V who used a feeding tube and had the lowest estimate of mental age, required most health care resources, used most medications, had most respiratory problems and had lowest global health scores. The study also revealed that there was a relationship among different measures of health status such as the CHQ, functional abilities, use of resources, and mental age.

A study was conducted by Wake, Salmon, and Reddihough (2003) with the aim of describing child health and well-being across the spectrum of cerebral palsy (CP) and to report on psychometric properties of the Child Health Questionnaire (CHQ) in this population. Parents of 80 individuals (45 males, 35 females between age range 5 to 18 years) attending a CP clinic in Victoria, Australia were surveyed. CHQ PF-50, a 50-item was used to assess the parent-reported heath status; GMFCS was used to assess the severity of impairment; based on previous assessments if available, or the judgment of three experienced pediatricians if assessments were not available epilepsy and feeding by gastrostomy were recorded as present or absent; and cognitive ability was recorded as normal or as mild, moderate, or severe intellectual disability. CHQ data were compared with normative data collected in Victoria two years earlier. The CHQ demonstrated good psychometric properties for children with CP. Children with CP had markedly poorer health on every CHQ scale than those in the normative sample. Health status did not vary by cognitive status or epilepsy. Children with severe CP had the poorest physical health, but psychosocial health and emotional impact on parents were similar for mild and severe CP showing that these should not be assumed to be less prevalent when CP is mild.

Another cross sectional study was conducted by Dickinson, Parkinson, Seiberer, and Schirripa (2007) to assess the self-reported QoL in 1174 children aged 8-12 years with CP selected randomly from 6 European countries. The KIDSCREEN instrument was used to assess the QoL which revealed that pain was common and this was associated with lower QoL on all domains. Bjornson, Belza, KartinLongsdon and Mclaughlin (2008) also showed that pain was experienced even by mild hemiplegic children with CP especially on the palsy affected side of their body. Impairments and pain explained up to

3% and 7%, respectively, of variation in QoL. Children with CP had similar QoL to children in the general population in all domains except schooling, in which evidence was equivocal.

Arnaud, Koning, Michelsen, Parkes, Parkinson, Thyne, and Beckung (2008) conducted a study to determine whether the type and severity of the child's impairment and the family's psychosocial, social and economic characteristics influenced parent-reported child QoL. A cross sectional survey was conducted in Europe involved 818 children with CP, aged 8-12 years from Europe. KIDSCREEN questionnaire was used to assess parent reported child QoL. The data for each of the 10 domains were analysed separately. The results revealed that the parental response rates were high (93%–97%) for all domains except the financial domain (79%). Gross motor function and IQ level were independently associated, positively or negatively, with almost all domains, respectively. Children with severely impaired motor function were more likely to have poor QoL in the physical well-being and autonomy domains. Similarly, children with lower IQ were at higher risk of having a poor QoL in the social support domain. However, greater severity of impairment was not always associated with poorer QoL; in the moods and emotions, social acceptance, self-perception and school environment domains, less severely impaired children were more likely to have poor QoL. The risk of poor QoL in terms of social acceptance and school environment decreased with increasing severity of gross motor impairment. Similarly, children with an IQ of 50 were less likely to have poor QoL in the moods and emotions and self-perception domains than were other children. In the domains physical and psychological well-being and self-perception, pain was found to be associated with poor QoL. It was also found that parents with higher levels of stress were found to have poorer QoL in all domains which suggests that parent's report of the QoL may be influenced by the factors other than the severity of the child's impairment.

Manus, Corcoran and Perry (2008) conducted a cross sectional study to find the association between participation in everyday activities and QoL independent of age, gender and level of impairment in children with CP between the ages 8-12 years. Frequency of Participation (FPQ) and KIDSCREEN was completed by parents of 98 children with CP. It was found that independent of age and gender there was a significant decrease in the overall participation with increasing level of impairment. In general children with CP reported high QoL. Increase in impairment is associated with diminished QoL in two domains- Physical well-being and social support and peers and overall participation was significantly associated with QoL in three of the ten domains (physical well-being, social support and peers & moods and emotions).

In a study which was done by Remo, Emma, Michelle, Eric, Tim, and Maria (2008) to investigate the self-esteem, self-concept and QoL in children with hemiplegic CP (HCP) in comparison with the typically developing peers, a total of 86 children in the age range between 3-16 years with HCP and age and sex matched peers participated. Self-Perception Profile for children (Harter, 1985) and the Pictorial Scale of Perceived Competence and Social Acceptance for Young Children (Harter & Picke, 1984) were used to measure the self-esteem/concept and QoL was measured using the Pediatric Quality of Life Inventory, version 4. Significant differences in scores favouring the peer group were found for physical competence, athletic competence, and scholastic competence, but favored children with HCP for maternal acceptance. QoL was significantly higher for the peer group for both parent and child scales. It was concluded that children with HCP experience reduced QoL and self-concept compared to typically developing peers.

A study was carried out by Koning, Grandjean, Colver, and Arnaud (2008)to compare the reports of parents and professionals of the QoL of 8 to 12-year-old children with CP and associated intellectual impairment from several countries in Europe and also to determine the factors associated with low child QoL according to the parents and professionals. Professional (teacher, therapist, or residential carer) and parent reports of QoL for 204 children (127 males, 77 females with CP were obtained in nine European regions, using the KIDSCREEN questionnaire. GMFCS was used to classify the motor function and two items from the Child Health Questionnaire was used to assess pain by the parents and professionals. Parenting Stress Index⁄Short form was used to assess the parental stress. It was found that high parental stress was significantly associated with low parent-reported QoL in all the domains. Parents of children with severe physical impairment were significantly more likely to report poor QoL for their child in the (physical, social support and autonomy domains). Child pain (parent-reported) was associated with low child QoL in the physical and psychological domains. Parents with a university degree were significantly more likely to report lower QoL for their child in the parental relations domain. None of the variables tested was significantly associated with parent-reported child QoL in the social acceptance domain. In the professionals proxy-reports, the severity of the child’s physical impairment was associated with lower child QoL in the physical, autonomy and psychological domains.

A study was conducted by Melisa Seer Yee Lim and Chee Piau Wong (2009) to study the impact of HRQoL of CP in the lives of patients and their families. A total of 27

(13 males and 14 females) patients in the age range between 3 years 8 months old to 10 years 11 months old were interviewed. The participants were divided into groups of three ethnic distribution: Malays (44%), Indian (30%), Chinese (22%), others (4%). Lifestyle Assessment Questionnaire-Cerebral Palsy (LAQCP), was used to interview the parents. Results revealed that three (11.1%) patients reported severely affected QoL. Seven (25.9%) patients reported moderately affected QoL and 10 (37%) reported mildly affected QoL. The worst score of 76 were reported in 2 patients. The best score of 11 was reported in one patient. A comparison was made to see if there was any correlation between age and lifestyle assessment score which indicated very little correlation between the three groups. The study also compared between both gender groups and also between each gender group and overall group which indicated insignificant results. It was concluded that impairment and disability due to CP is likely to be similar in both developing and developed countries. However, the quality and type of care received by patients are likely to determine the resultant handicap and the implication on the QoL.

A study was conducted by Thurston, Paul, Loney, Wong, and Browne (2010) to determine the QoL, associations and costs of a multi-diagnosis group of children with special needs. Families with the children in the age range of 2-19 years with multi-diagnosis group of special needs were eligible for the study. QoL was measured using the Pediatric Quality of life Inventory (Varni, 2007). The questionnaire was administered in a total sample of 429 mothers of children with CP. It was revealed that QoL were lower in this group when compared to the healthy and single disorders groups of children. The QoL scores decreased with advancing age. Child psychosocial well-being was more strongly associated with child/family variables compared to physical well-being and the health utilization costs were higher in children with greater physical challenges.

A cross sectional study was conducted by Elizabeth (2010) to measure the self-reported QoL, to extract the domain specific effect on the QoL and to compare the QoL across two age groups using CPQOL questionnaire. This questionnaire assessed five domains social wellbeing, emotional wellbeing, functioning, pain and impact of disability, participation and physical health. A total of 45 subjects with CP (19 males and 26 females) who were attending regular school, the Rehabilitation unit of tertiary hospital in Karnataka and also from various rehabilitation centres for physically challenged in Kerala were included in the study. They were grouped in two groups, where group 1 included children within the age range of 9-11 years and group 2 included children within the age range of 12-13 years. Results revealed that the domains such as social wellbeing, emotional wellbeing and functioning had the highest scores while the domain of pain and impact of disability, participation and physical health had the lowest scores. Similar scores were obtained in both the genders. For all the five domains children in the age range between 12-13 years reported a poor QoL in comparison with the other age group i.e., 9-11 years.

A study was conducted by Tella, Gbiri, Osho, and Ogunrinu (2011) to evaluate the impact of CP HRQoL of Nigerian children. Totally 54 children (33 males and 21 females) with CP, between the age range of 1 and 12 years participated in the study. The CHQ Parent Form 28 was used in order to assess the HRQoL. The questionnaire was completed by their parents, guardians or primary care-givers. GMFCS was used to assess the severity of motor disability. The participants scored very low on each domain of

CHQ-PF 28 which indicated that children with CP had a reduced HRQoL, and the degree to which it is reduced was directly related to the age and severity of the CP. They concluded that increasing age and severity of the CP had a negative impact on physical function, social role/behaviour, parenting impact (time/ emotion), children's health and their psychosocial function.

A study was conducted by Abanto, Carvalho, Bonecker, Ortega, Ciamponi, and Ragio (2012) to assess the parental reports of the oral HRQoL of children with CP. Initially a total of 75 children from 6-14 years of age were identified from which the final sample comprising of 60 children with CP and their respective parents were drawn. The parents were invited to answer two questionnaires: one on the children's OHRQoL and another on socioeconomic conditions. The OHRQoL instrument used in the study was the Brazilian version of the Parental Caregivers Perceptions Questionnaire (P-CPQ, Aleksandra 2004) and the Family Impact Scale (FIS, Locker, 2002). According to parent's perceptions 10%, 10%, 35%, 40% and 2% of the parents assessed their children's oral health as “excellent”, “very good”, “good”, “fair” and “poor” respectively. On the question whether the overall well-being of their children was affected by the oral/orofacial conditions, 43%, 15%, 20%, 17% and 5% reported "not at all", "very little", "some", "a lot" and "very much", respectively. It was revealed that the severity of the type of CP, its reduction of communication ability and seizures showed a negative impact on oral symptoms and functional limitation domains. It was concluded that the severity of dental caries, communication ability and low family income were conditions strongly associated with a negative impact on OHRQoL of children with CP.

A study was done by Chang, Lin, Tung, and Chang (2012) to study the association between drooling in children with CP and their HRQoL and factors that predict the variability of HRQoL in these children. Children with CP in the age range between 2 to 6 years without drooling who scored a ranking of 2 according to the Drooling Rating Scale developed by Thomas-Stonell and Greenberg, were the control group. They had a drooling ranking score >2, were the study group. A total of forty-seven children participated in the study: 14 did not drool and 33 did drool. Pediatric Quality of Life Inventory Version 4.0 was used to assess the HRQoL. Developmental Screening Test was used to assess the developmental status of the children rated by the parents or primary caregivers. This test evaluated five developmental domains (language, social-personality, gross motor, fine motor, and cognition). It was found that the physical health and psychosocial health summary scores of the children that drooled were found to be lower than for the children who did not drool. There was a negative correlation of the drooling ranking score with the physical health summary score and the psychosocial health summary score. It was concluded that drooling was associated with a lower HRQOL. The Prediction of the physical health summary score was more closely associated with the drooling ranking scores and gross motor development and the psychosocial health summary score was found to be more closely associated with the language development of children with CP.

A study was conducted by Sanna, Varho, Maenpaa, Forsten, Autti-ramo, and Haataja (2013) to assess the QoL of Finnish children with CP, both from the child's and the caregiver's point of view and to analyse the effect of background factors on QoL. The study was carried out as a part of a national CP research project using a validated questionnaires CP QoL-Child (Davis, Waters & Mackinnon, 2007). 128 questionnaires were given to caregivers who had a 4 to 12 year-old child with CP and children between 9-12 years were asked to fill in the child-self-report version. Response rate of 61% were obtained from 78 guardians and 27 children in both the cases. The overall QoL was reported to be good in Finnish children with CP. The correlation of QoL scores between the caregivers and children was good except in the domain of pain and the impact of disability. Parental estimates were consistently lower in all domains. Regarding the background factors, all the functional classification scales were associated inversely with QoL in both groups. It was concluded that despite the good overall QoL, CP is perceived to limit participation and pain impaired QoL.

A cross sectional study was conducted by Badia, Riquelme, Orgaz, Acevedo, Longo, and Montoya (2014) to assess the 'health professional's perceptions' of the impact of pain on HRQoL of children and adolescents with CP. Forty-five physiotherapists who were treating children and adolescents with CP on a regular schedule were contacted and 35 of them (78%) decided to participate in the study. Physiotherapists' reports from 91 individuals with CP were obtained. The sample composed of girls (54.9%) and boys (45.1%) with a mean age of 12years (range between 8 and 19 years). The physiotherapists were asked to complete a questionnaire concerning socio demographic and clinical characteristics (pain, motor function and HRQoL) of individuals with CP. Physiotherapists reported presence and severity of pain in individuals with CP by using the SPARCLE Study of Participation of Children with Cerebral Palsy Living in Europe protocol (2013) and classified the level of motor function using the GMFCS. Physiotherapists also assessed the HRQoL in children and adolescents with CP by using the Spanish version of the KIDSCREEN (Ravens-Sieberer, Gosch, Rajmil, et al., 2005).The Physiotherapists reported that 51 % of individuals with CP suffered from the pain and also perceived that pain in individuals with CP was responsible for the reduction of the psychological but not physical domains of HRQoL.

A study was conducted by Law, Hanna, Anaby, Kertoy, King, and Xu (2014) with the aim of describing the overall patterns of HRQoL, examining the changes in parent's perceptions of child's HRQoL across 18 months and exploring factors that predict these changes. Totally 427 parents of children (229 boys and 198 girls) with a physically based disability between the ages 6 to 14 years participated in the study. The CHQ was administered to assess the health and QoL of children from caregiver's perspective, Strengths and Difficulties Questionnaire (SDQ) was used to measure behaviour of the child, the Short Form-36 (SF-36) was used to measure Parents' health. Activities Scale for Kids (ASK) was used to measure the physical functioning and daily task performance and Craig Hospital Inventory of Environmental Factors (CHIEF) was used to measure environmental barriers. It was revealed that children with physical disabilities differ from that of the normative group on parent ratings of their physical and psychosocial health. While there was little average change in CHQ scores over 18 months, there was evidence of heterogeneity among children. Factors such as environmental barriers, family functioning/impact, child physical functioning and behavioural difficulties and general health significantly influence QoL scores as measured by the CHQ.

A study was conducted by Dobhal, Juneja, Jain, Smitha, Sairam, and Thiagarajan (2014) in New Delhi to determine the HRQoL in children with CP using a Lifestyle Assessment Questionnaire (LAQ-CP, Mackie, Jessen & Jarvis, 1998). The questionnaire was translated in Hindi language and given to the parents to administer. Children in the age group of 3-10 years diagnosed with CP and receiving regular physical/occupational therapy for a duration of 1 year participated for the study. It was revealed that 9% patients had good, 24% had mildly affected, 37% had moderately affected, and 30% had severely affected HRQoL. Lifestyle Assessment Score (LAS) was significantly greater in boys when compared to girls, and significantly more in subjects with quadriplegic CP, seizure disorder, visual problems, cognitive deficits and feeding problems. The physical independence, mobility and social integration dimensions of HRQoL were much more severely affected than the clinical burden, economic burden and schooling dimensions. It was concluded that HRQoL was significantly affected in most majority of the patients with CP.

A study was carried out by Colver, Rapp, Eisemann, et al., (2015) to assess the self-report QoL in adolescents with CP and its variation with respect to impairment when compared against matched controls. A total of 818 children in the age range between 8–12 years were interviewed in 2004-05 and followed up in 2009-10 in the age range between 13-17 years. All the participants were assessed using different scales such as the KIDSCREEN questionnaire to assess the QoL, Strengths and Difficulties Questionnaire to assess the psychological problems in children with CP, and Parenting Stress Index to assess the level of stress in parents of children with CP. It was found that severity of impairment was significantly associated with low QoL on three domains i.e., (Moods and emotions, Autonomy, and Social support and peers) and adolescents with CP were found to have significantly low QoL than the control group in only one domain (Social support and peers). Pain was found to have strong association with low QoL on eight domains. Childhood QoL was found to be a consistent predictor of adolescent QoL. The Child psychological problems and parenting stress in childhood could predict small reductions in QoL. Adolescents with high parental scores in their childhood had significantly lower QoL than other adolescents in five domains. Adolescents who had psychological difficulties in childhood had lower QoL than did other adolescents in all domains apart from self-perception and relationships with parents.

Thus the existing literature revealed that QoL which is an important aspect of the overall physical, mental/emotional and social well-being is affected in children with CP. This reduction in QoL could result because of the physical impairment seen in children with CP. Several other factors including the level of disability of the child, type and severity, pain, associated problems, level of support and parental stress could influence the QoL.

Although several studies have been carried out to assess the QoL in children with CP using different tools and from different ethnic background, very few of these studies have associated it with variables such as topographical distribution, duration of intervention and associated problems. Variation in QoL across age groups and gender also have been less researched. Moreover some of the studies reported that QoL is good in children with CP while other studies report that it was affected. Further there are very limited studies conducted especially in Indian context to assess the QoL in children with CP.

Thus a need was felt to assess the QoL in various domains important in the life of the child with CP. These measures can help identify individual priorities that are problematic so that therapeutic objectives and programs may be aligned according to the needs of the patient and caregivers, since the goal of most intervention for these children is to preserve or improve the QoL. Keeping this in view, the present study was planned with the aim to assess QoL in children with CP.

Chapter 3

Method

The present study aimed at assessing quality of life in children with cerebral palsy in the age range of 4-12 years with regard to different domains using the Cerebral Palsy Quality of Life Questionnaire. The study was undertaken in the following phases:-

Phase I: Adaptation of the quality of life questionnaire to the Indian context.
Phase II: Administration of the questionnaire on mothers/caregivers of children with cerebral palsy.
Phase III: Assessment of test-retest reliability.

Phase I: Adaptation of the quality of life questionnaire to the Indian context.

As a part of construction, the following research steps were undertaken:

Step 1: Adaptation of the Questionnaire

This step involved the adaptation of the preliminary version of a Cerebral Palsy Quality of Life Questionnaire for children (CP QOL-Child, Version 2, Waters, Davis, & Boyd, 2013, primary caregiver questionnaire 4-12 years) for the assessment of perspectives of the parents/caregivers regarding the difficulties faced by their children with cerebral palsy. This questionnaire was selected in the present study since several researchers have reported that the internal consistency and construct validity was good for all the domains and it provided more comprehensive assessment of the QOL of children with CP in comparison with the performance of other questionnaires. Davis, Shelly, Waters, and Davern (2010) reported that conceptually and psychometrically CP QOL-Child performed more strongly than other questionnaires for children with CP.

Each statement was assessed for its usefulness in the Indian context. The statements in this questionnaire focused on the physical, health, social, academic, financial problems faced and the impact of these on the day to day activities and on the overall quality of life of the child. The statements were grouped under seven domains such as Family and Friends, Participation, Communication, Health, Special Equipment, Pain and Bother, and Access to Services. Below mentioned are a few sample statements that are included under the seven mentioned domains:

I. Family and Friends

How do you think your child feels about…

1. the way they get along with people of all age groups
2. the way they get along with you
3. the way they get along with other children at preschool or school

II. Participation

How do you think your child feels about…

1. their ability to participate at preschool or school
2. their ability to participate in recreational activities
3. their ability to participate in their community

III. Communication

How do you think your child feels about…

1. the way they communicate with people they know well
2. the way they communicate with people they don’t know well
3. the way other people communicate with them

IV. Health

How do you think your child feels about…

1. their physical health
2. the way they get around (mobility)
3. their ability to keep up academically with their peers

V. Special Equipment

How do you think your child feels about…

1. the special equipment they have at home (e.g., special seating, wheelchair etc.)
2. the special equipment they have at their school (e.g., special seating, wheelchair etc.)
3. the special equipment that is available in the community (ramps, escalator etc.)

VI. Pain and Bother

1. Is your child bothered by hospital/clinic visits
2. How much pain does your child have
3. How much discomfort does your child experience

VII a. Access to Services

How do you feel about…

1. your child’s access to medical treatment
2. your child’s access to therapy (e.g., physiotherapy, speech therapy, occupational therapy).
3. your child’s access to extra help with learning at preschool or school.

VII b. About Yourself

How do you feel about…

1. Your physical health
2. Your work situation?
3. Your family’s financial situation?

A rating scale to assess the problems objectively was also prepared on the lines of the original questionnaire to rate the responses obtained from the parents in order to obtain an objective score. A few statements were accompanied with response choice of[“very unhappy” (a score of 0), “unhappy” (a score of 1), “neither happy nor unhappy” (a score of 2), “happy” (a score of 3), “very happy” (a score of 4)] while others were accompanied with response choice of [“always” (a score of 0), “often” (a score of 1), “sometimes” (a score of 2), “rarely” (a score of 3), “never” (a score of 4)], [“great pain” (a score of 0), “lot of pain” (a score of 1), “some pain” (a score of 2), “a little pain” (a score of 3), “no pain at all” (a score of 4)] etc. This preliminary version of the tool developed had a total of 65 items with 16 in the Family and friends, 5 in the Participation, 3 in Communication, 16 in Health, 3 in Special equipment, 13 in Pain and bother, 9 in Access to services domains.

Step 2: Content validity check

The content validity of the preliminary version of the Cerebral Palsy Quality of Life questionnaire and the rating scale was assessed by obtaining the feedback from three experienced speech-language pathologists. They were asked to judge the appropriateness of the items included and the rating scale used. The feedback was collected using a 3 point rating scale ranging from the contents are not very valid (score 0) to all the contents are valid (score 2).

Initially the questionnaire contained 66 items which were reduced to 61 items after content validation. Only in the health domain the items were reduced from 16 to 11. The items in each domains which obtained a score of 1 or 2 were retained and the items which obtained a score of 0 were deleted from the questionnaire. The items which were very general were modified specifically and the items in which the parents would have difficulty in answering were deleted from the questionnaire e.g., (their life in general, themselves, their future, opportunities in life etc.) The items containing ambiguous statement were deleted. The rating scales was also modified for a few questions. The content and the structure of the sentences were also modified as per the suggestions given by the professionals.

The final English version of the CP QOL- CHILD was translated into Kannada and Malayalam languages. The process of translation was carried out in the following steps: 1) translation into Kannada and Malayalam; 2) reverse translation 3) final translation. At first, two translators of the respective languages had independently translated the CP QOL-Child from English to Kannada and Malayalam languages. Both had Kannada and Malayalam as their native language.

In the second step, a reverse translation was carried out where two other persons who were a native of these two languages and had a good proficiency in English were requested to carry out the reverse-translation, that is, the Kannada and Malayalam translation were translated back into English and it was ensured that the content had not been modified during the process of translation. The reverse translation materials were then checked in order to identify and correct for the semantic, idiomatic and conceptual discrepancies. In the third step, a review and comparison between corrected version back-translated of the questionnaire with the original English version was performed in order to generate the final translation.

Step 3: Pilot study

A pilot study was carried out in which this questionnaire was administered on three parents/caregivers of children with cerebral palsy in the different age groups between 4-12 years to verify if all the items were understandable and satisfactory. Children with different types of cerebral palsy were included. The responses obtained were documented and grouped under different domains. After the pilot study it was found that there was a need to simplify few questions and include examples under a few items in the questionnaire for better understanding of the questions by the parents/caregivers.

Step 4: Finalization of the final version of the Questionnaire:

The final version of the questionnaire was prepared after the pilot study. The final form of the questionnaire had a total of 61 items with 15 items in Family and Friends, 5 items in Participation, 3 items in Communication, 11 items in Health, 3 items in Special Equipment, 12 items in Pain and Bother, and 12 items in Access to Services. The first six domains were grouped under section one since it assessed the child's feelings about the different aspects of their life and the 7th domain was grouped under section II since it assessed the caregiver's feelings about their child's access to therapy facilities and about the caregivers themselves.

Phase II: **Administration of the questionnaire on parents of children with cerebral palsy**.

The final version of the Cerebral Palsy Quality Of Life Questionnaire was administered on the parents of 46 children with cerebral palsy in the age range of 4-12 years. The details of the participants have been provided below:

Participants

A total of 46children with cerebral palsy (17 females and 29 males) between the age-range of 4-12 years who reported to the Department of Clinical Services, AIISH, Mysore and who had Kannada and Malayalam as their native language were considered for this study. They were diagnosed as having Delayed speech and language with cerebral palsy by a qualified team of professionals including the speech and language pathologist, physiotherapist, paediatrician and a clinical psychologist. They were grouped based on age in which they were assigned under three groups (4-6, 7-9 and 10-12 age range), gender, topographical distribution, duration of intervention undertaken and associated problems. There were 21 children in the age group (4-7 years), 9 in (7.1-10 years) and 16 in (10.1-12 years). There were 37 children with spastic type of CP, 8 with flaccid type of CP and 1 with dystonic type of CP. There were 23 children with quadriplegia, 11 with paraplegia, 9 with hemiplegia, 2 with triplegia, 1 with monoplegia and. All the participants included were enrolled in an intervention program.27 participants had attended speech language intervention and physio/occupational intervention for a duration of greater than one year and 19 children attended intervention for a duration of less than a year. Some children with CP had no associated problems while others had a few associated problem such as the visual impairment, mental retardation, seizure disorder, etc. There were 11 children who had no associated problem, 12 who had only one associated problems and 23 who had more than one associated problems. The socioeconomic status scale developed by Venkatesan (2009) was used to assess the socio economic status of participants. They belonged to low, mid and high SES groups. The scale included section such as occupation and education of the parents, annual family income, property, and per capita income to assess the socio economic status of the participant. The severity of motor disability was also assessed and classified using the Gross Motor Function Classification System (GMFCS) ranging from I to V severity groups. Level I indicated walks without limitations, level II indicated walks with limitations, level III indicated walks using a hand-held mobility device, level IV indicated self-mobility with limitations; may use powered mobility and level V indicated transported in a manual wheelchair. There were 3 children grouped under level I, 11 children under level II, 6 children under level III, 12 children under level IV, and 14 children under level V. All ethical standards were met for participant selection and their participation. Prior to testing, a written consent as obtained from the parents of the participants after explaining the purpose of the study.

Procedure

The participants were selected based on the above mentioned criteria. The testing was carried out in a relatively noise free environment with minimum distractions. A rapport was built with the mother/caregiver and the purpose of the study was explained to them. They were made to sit individually and fill the final version of the cerebral palsy quality of life questionnaire. Additional clarification was provided to the parents wherever necessary. The responses obtained from the parents/caregivers were documented based on the rating scale. The time taken to administer the questionnaire was approximately 35 minutes. Positive reinforcement like verbal, social and token reinforcements were provided to the children after the administration.

Phase III: Assessment of test-retest reliability

To assess the test-retest reliability, the questionnaire was administered again on 10 of the participant sample after a duration of one week.

Analysis

The score obtained from each participant was totaled. Domain specific scores were obtained and a total score of the domains were obtained.

Statistical Analysis

These scores were averaged across all the participants and fed to the computer for statistical analysis. Cronbach’s alpha was used to determine the test- retest reliability. Descriptive statistics was used to obtain mean, median and standard deviation of scores obtained on the questionnaire. Shapiro Wilk test was carried out to check for normality for in all domains. Mann-Whitney test was used to find significant difference across group. MANOVA and oneway ANOVA was used to compare QoL across age group. Kruskal-Wallis test was used to compare scores across variables which were not normally distributed. Pearson's correlation test was used to assess the relation between QoL scores across different sections, between other section and caregivers section. The results obtained have been presented and discussed in the next chapter.

Chapter 4

Results

The present study aimed at assessing the quality of life (QoL) of children with cerebral palsy (CP) in the age range of 4-12 years across different domains such as Family and Friends, Participation, Communication, Health, Special Equipment, Pain and Bother and Access to Services. The specific objectives of this study were to compare domain wise score of QoL obtained on the questionnaire, to compare between QoL scores and severity of CP, to compare QoL between different topography viz., quadriplegia, paraplegia, hemiplegia, to compare QoL between different age groups viz., 4-7 years, 7.1-10 years and 10.1-12 years, to compare the QoL across gender, to assess the effects of associated problems on QoL and to assess the influence of intervention on QoL.

The adapted version of the CPQoL questionnaire for children [CPQoL-Child, version 2 Waters, Davis, & Boyd (2013), primary caregiver questionnaire 4-12 years] was administered on the caregivers of 46 children with CP in the age range of 4-12 years and the responses obtained were scored on a four point rating scale where a score of 0 signified ‘very unhappy’, a score of 1 signified ‘unhappy’, a score of 2 signified ‘neither happy nor unhappy’, a score of 3 signified ‘happy’ and a score of 4 signified ‘very happy’. The first six domains in section I assessed the child’s feelings about the different aspects of their life and the 7th domain in section II assessed the caregiver’s feelings about their child’s access to therapy facilities and about the caregivers themselves. The scores obtained from each participant for different domains were totalled. The data thus obtained was tabulated and analyzed using the SPSS (Statistical Package for the Social Sciences)-Version 21.0 software. The statistical procedures which were carried out have been mentioned below:-

- Cronbach's alpha test was used to obtain test-retest reliability.
- Descriptive statistics was used to obtain mean, median and standard deviation.
- Shapiro Wilk test was carried out to check for normality.
- Mann-Whitney test was used to find significant difference in scores across gender in each age group, duration of intervention and topographical distribution.
- MANOVA was used to compare QoL between age groups across specific domains.
- Oneway ANOVA was used to compare total QoL of all domains between age groups.
- Kruskal-Wallis test was used to compare scores across variables which were not normally distributed across the age groups (4-7 years, 7.1-10 years, 10.1-12 years), between children with and without associated problems, across three topographical groups (quadriplegia, paraplegia, hemiplegia), between QoL and different severity groups (I-V).
- Pearson's correlation test was used to assess the relation between first section (D1 to D6) and second section (caregivers section, D7a & D7b).

The results acquired from the above mentioned statistical measures have been presented and discussed under the following sections:-

I. Test retest reliability

II. Total and domain wise score of QoL obtained on the questionnaire
III. Comparison between QoL scores and severity of CP
IV. Comparison of QoL in children with different topographical distribution
V. Comparison of QoL between three age groups (4-7, 7.1-10, 10.1-12 years)
VI. Comparison of QoL across gender
VII. Comparison of QoL in children with and without associated problems.
VIII. Comparison of QoL between children who had undergone intervention for a duration of less than a year and those with intervention duration greater than 1 year

I. Test-retest reliability

The test-retest reliability was determined for 10 children with CP using Cronbach’s alpha by re-administering the questionnaire on their caregivers. The alpha values obtained on the total scores of the domains D1 to D6, which were Family & Friends, Participation, Communication, Health, Special Equipment, Pain and Bother was found to be strong, i.e., 0.86 and the total scores of the domain D7a and D7b (Access to services, About yourself) was 0.85. The overall total scores of all the domains (D1-D7) on the questionnaire was 0.8 which indicated highly significant test-retest reliability.

II. Total and domain wise score on the questionnaire

The raw score obtained on all the seven domains were totalled for all the participants. Descriptive analysis was used to calculate the mean and standard deviation. The total mean score across all the domains obtained across all participants was 59.29 (SD=9.89). The scores obtained on different domains viz., family & friends, participation, communication, health, special equipment, pain and bother, access to services, and about self were compared. The raw score obtained for each domain was expressed as percentage score since the number of questions in each domain were different. The total mean percentage of QoL and standard deviation obtained across all the domains (D1-D7) have been depicted in the table 4.1. The mean percentage scores of QoL was higher on the domain D1 (Family & friends), followed by D6, D4, D7a, D2, D7b, D3 and the least scores were obtained on the domain D5 (Special Equipment). An attempt was made to derive a criteria to classify the QoL of the participants based on the scores obtained. However since the mean scores clustered together ranged from 45.11 to 65.79, a classification could not be arrived at. In order to interpret the QoL of the participants, the criteria as per the Lifestyle Assessment Scale (LAQ-CP Mackie, Jessen, & Jarvis, 1998) has been borrowed. The classification of QoL based on LAS is as follows: Good (>70%), mildly affected (51-70%), moderately-affected (30-50%), severely affected (<30%). As per this scale, the QoL of the participants in the present study can be interpreted to be mildly affected. Moreover, the QoL on all domains also was mildly affected except D5 which was moderately affected. The mean percentage across all domains have been depicted in fig 4.1.

Table 4.1:

Total mean percentage and standard deviation (SD) of QoL obtained across all the domains in children with CP.

Domains	**Total mean %**	**SD**
Family & friends (D1)	65.79	15.97
Participation (D2)	65.11	18.51
Communication (D3)	63.76	18.94
Health (D4)	52.31	16.52
Special Equipment (D5)	45.11	26.21
Pain & Bother (D6)	58.51	14.98
Access to services (D7a)	61.87	14.75
About yourself (D7b)	54.45	17.00
Total	59.29	9.89

Values are given as Total Mean±SD

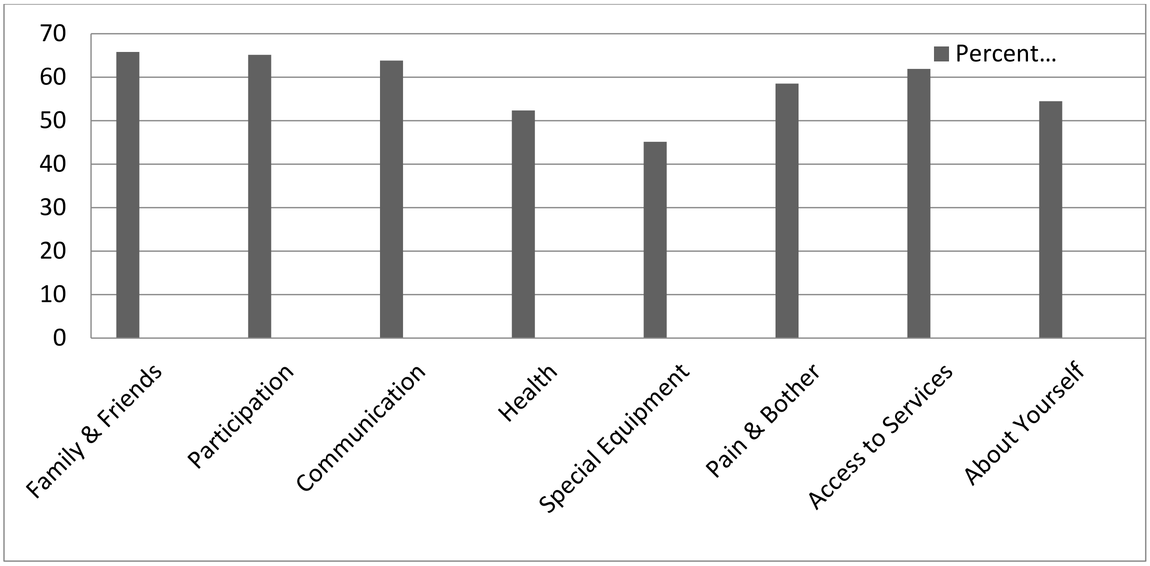

Figure 4.1: Total mean percentage scores of QoL obtained across all the domains in children with CP.

Since the first six domains was about the child's perspective about QoL and the seventh domain was about the caregiver's perspective about access to services and about himself or herself, Pearson's correlation was carried out to check the correlation between the domain D1 to D6 with domain D7a (access to services) and D7b (about yourself). The results revealed that there was a significant correlation between the domains D1 to D6 and D7a and D7b. The r and p values have been depicted in the table 4.2.

Table 4.2:

Results of Pearson's correlation obtained between the first six domains of QoL and D7a, D7b and D7ab in children with CP.

Domain	**D1-D6**	
	r	**p value**
D7a	0.42	* 0.00
D7b	0.32	* 0.03
D7ab	0.43	* 0.00

*Values are given as Mean±SD *p<0.05, D1 D1=Family & Friends, D2=Participation, D3=Communication, D4=Health, D5=Special Equipment, D6=Pain & Bother, D7a=Access to services, D7b= About Yourself.*

In addition to find whether parent/caregiver stress influenced the rating, a questionnaire to assess stress was administered. The total raw score obtained for all participants were totalled. Pearson's correlation was used to check the relation between QoL scores and parental stress scores across all the domains. The results revealed that there was a significant correlation only between the domains D7a, D7b and the subtotal D7ab. This indicated that stress influenced the caregiver rating on the CPQoL questionnaire only on D7 which includes the access to therapy facilities for their children and about themselves. On the other domains, the parental stress did not influence the QoL scores. Since domain 7b involved questions about the caregiver, it showed a negative correlation i.e., higher stress with low QoL.

III. Comparison between QoL scores and severity of CP

The severity of CP was assessed using GMFCS. Level I indicated walks without limitations, level II indicated walks with limitations, level III indicated walks using a hand-held mobility device, level IV indicated self-mobility with limitations; may use powered mobility and level V indicated transported in a manual wheelchair. The level I to V ranged from least to maximum severity. The severity scores ranging from I-V were compared with QoL scores across all the domains. There were 3 children in level I, 11 in level II, 6 in level III, 12 in level IV, and 14 in level V. Shapiro Wilk test was carried out to check for the normality for all the domains across different severity levels and it was found that the data was not normally distributed due to unequal sample and high standard deviation. The mean percentage and standard deviation scores obtained have been depicted in table 4.3. On comparison, it was seen that the mean total scores were highest for children in the level I indicating better QoL in children with less severity. The mean scores in all the domains were also highest for the children in level I except in the domains D2, D3, D5, and D7a. Across other levels, the total mean scores were comparable with level III having the least QoL. To check whether a significant difference existed between the five groups, Kruskal-Wallis test was carried out which revealed no statistically significant difference ($p>0.05$) in all the domains across different severity levels. The χ^2 values have been depicted in the table 4.4. The scores obtained across different severity levels in all the domains have been depicted graphically in figure 4.2.

Table 4.3:

Mean percentage and standard deviation (SD) for the scores of QoL in all the domains for children with different severity levels.

Domain	**N**	**I**	**N**	**II**	**N**	**III**	**N**	**IV**	**N**	**V**
D1	3	72.78± 9.47	11	66.06± 18.95	6	54.16± 22.77	12	66.94± 9.39	14	68.09± 15.42
D2	3	60.00± 10.0	11	70.90± 14.45	6	65.83± 25.77	12	60.83± 21.08	14	65.00± 18.08
D3	3	55.5± 4.8	11	65.90± 17.66	6	63.88± 30.12	12	59.02± 17.57	14	67.85± 18.15
D4	3	61.3± 12.0	11	54.13± 12.39	6	57.95± 18.39	12	46.77± 21.74	14	51.29± 14.44
D5	3	16.6± 28.8	11	42.42± 26.99	6	51.38± 33.50	12	45.83± 22.33	14	49.99± 24.45
D6	3	74.9± 2.08	11	59.09± 16.09	6	49.99± 15.30	12	53.29± 11.69	14	62.64± 15.19
D7a	3	63.0± 11.4	11	60.71± 14.46	6	61.31± 22.41	12	58.92± 10.71	14	65.30± 16.12
D7b	3	60.0± 10.0	11	54.54± 18.90	6	59.16± 21.31	12	53.75± 16.94	14	51.79± 16.36
Total	3	63.44± 6.11	11	59.94± 11.39	6	56.55± 10.52	12	56.69± 9.99	14	61.29± 9.31

Values are given as Mean±SD; D1=Family & Friends, D2=Participation, D3=Communication, D4=Health, D5=Special Equipment, D6=Pain & Bother, D7a=Access to services, D7b= About Yourself.

Table 4.4:

Results of Kruskalwallis test across severity levels on all the domains.

Domain	$\chi^{2\ (4)}$	**P value**
D1	2.48	0.65
D2	2.32	0.68
D3	2.46	0.65
D4	3.41	0.49
D5	3.74	0.44
D6	8.14	0.09
D7a	1.24	0.87
D7b	1.92	0.75

D1=Family & Friends, D2=Participation, D3=Communication, D4=Health, D5=Special Equipment, D6=Pain & Bother, D7a=Access to services, D7b= About Yourself.

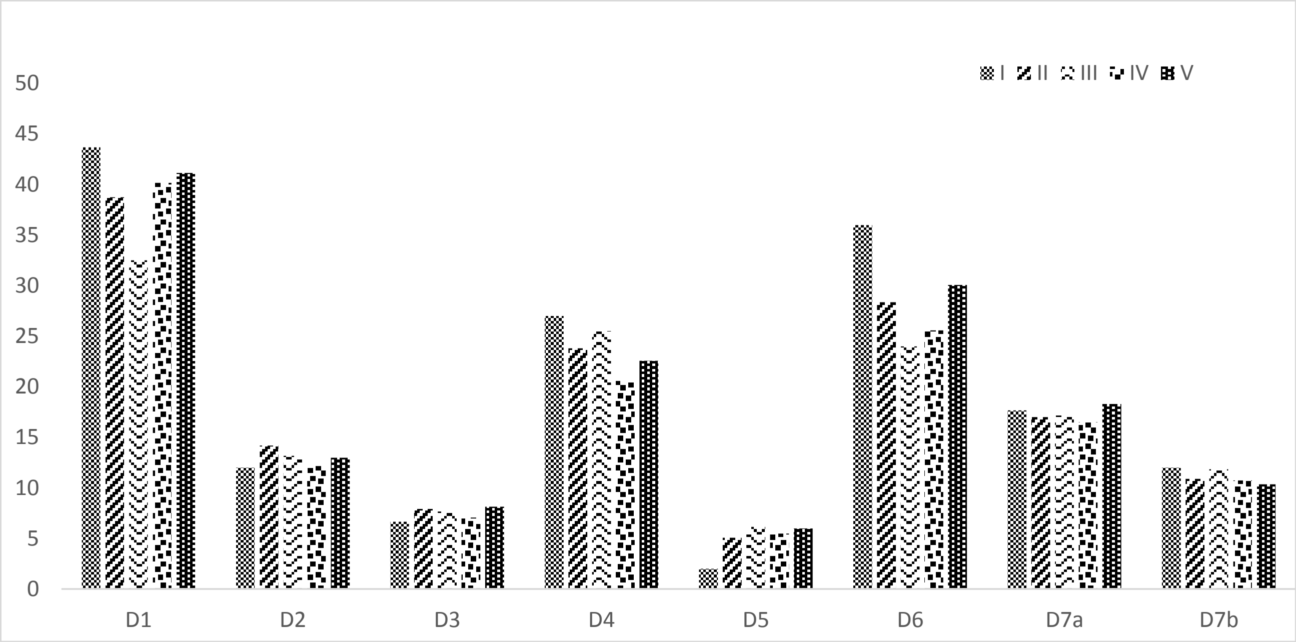

Figure 4.2. Mean percentage scores of severity levels across the domains.

IV. Comparison of QoL in children with different topographical distribution.

The effects of topography on the QoL was compared among three groups of children having quadriplegia, paraplegia and hemiplegia etc. There were 23 children in group 1 (Quadriplegia), 11 children in group 2 (paraplegia) and 9 children in group 3 (Hemiplegia). The children with other topographies were limited in number (less than 5) and hence were not considered for statistical analysis. Shapiro Wilk test was carried out to check for the normality for all the domains across different topography and it was found that the data was not normally distributed due to unequal sample and high standard deviation. The mean percentage and standard deviation obtained have been depicted in table 4.5. On comparison, it was seen that the mean percentage scores were higher for children paraplegia when compared to the other two groups indicating better QoL in children with group 2 (paraplegia). The mean scores were least for group 3 (hemiplegia) indicating poor QoL. When the mean scores of all the domains across the three groups were compared, it was seen that the group with paraplegia had higher QoL scores on all domains except D3, D6 and D7a. On D3 and D7a the group with quadriplegia had higher QoL scores and on D6, the group with hemiplegia had higher QoL scores. To check whether a significant difference existed between the three groups, Kruskal-Wallis test was carried out. Results revealed no statistically significant difference ($p>0.05$) in all the domains except for the domain 3 i.e., (communication) (χ^2 (2) =6.73, $p < 0.035$). The χ^2 values have been depicted in the table 4.6. Further Mann-Whitney test was carried out to check for the significant difference in domain 3 across the three groups which revealed no significant difference between the groups 1 & 2, and 2 & 3 ($p >0.05$). However there was a significant difference seen between group 1 and 3 ($z=2.65, p<0.05$). The mean percentage scores obtained across the domains of the three groups have been depicted graphically in figure 4.3.

Table 4.5:

Mean percentage and standard deviation (SD) values for the scores of QoL on all the domains for children with different topography.

Domain	**N**	**Quadriplegia**	**N**	**Paraplegia**	**N**	**Hemiplegia**
D1	23	65.79±16.67	11	68.93±10.73	9	59.25±20.90
D2	23	66.08±17.71	11	67.27±21.95	9	62.77±19.70
D3	23	68.84±15.73	11	66.66±22.36	9	48.14±18.53
D4	23	50.98±16.89	11	56.81±19.23	9	50.24±15.80
D5	23	47.82±28.33	11	48.48±20.69	9	32.40±28.69
D6	23	58.96±14.51	11	55.49±16.85	9	59.95±16.36
D7a	23	65.68±14.23	11	61.68±17.50	9	55.95±3.53
D7b	23	54.34±15.83	11	57.73±20.90	9	52.77±18.89
Total	23	60.18±8.98	11	60.83±11.84	9	54.98±11.13

*Values are given as Mean±SD *p<0.05; D1=Family & Friends, D2=Participation, D3=Communication, D4=Health, D5=Special Equipment, D6=Pain & Bother, D7a=Access to services, D7b= About Yourself.*

Table 4.6:
Results of Kruskalwallis test for different topography across different domains.

Domains	$\chi^{2(2)}$	**P value**
D1	2.26	0.32
D2	0.606	0.74
D3	6.73	*0.03
D4	2.00	0.37
D5	1.96	0.38
D6	0.77	0.68
D7a	12.62	0.21
D7b	0.59	0.74

D1=Family & Friends, D2=Participation, D3=Communication, D4=Health, D5=Special Equipment, D6=Pain & Bother, D7a=Access to services, D7b= About Yourself.

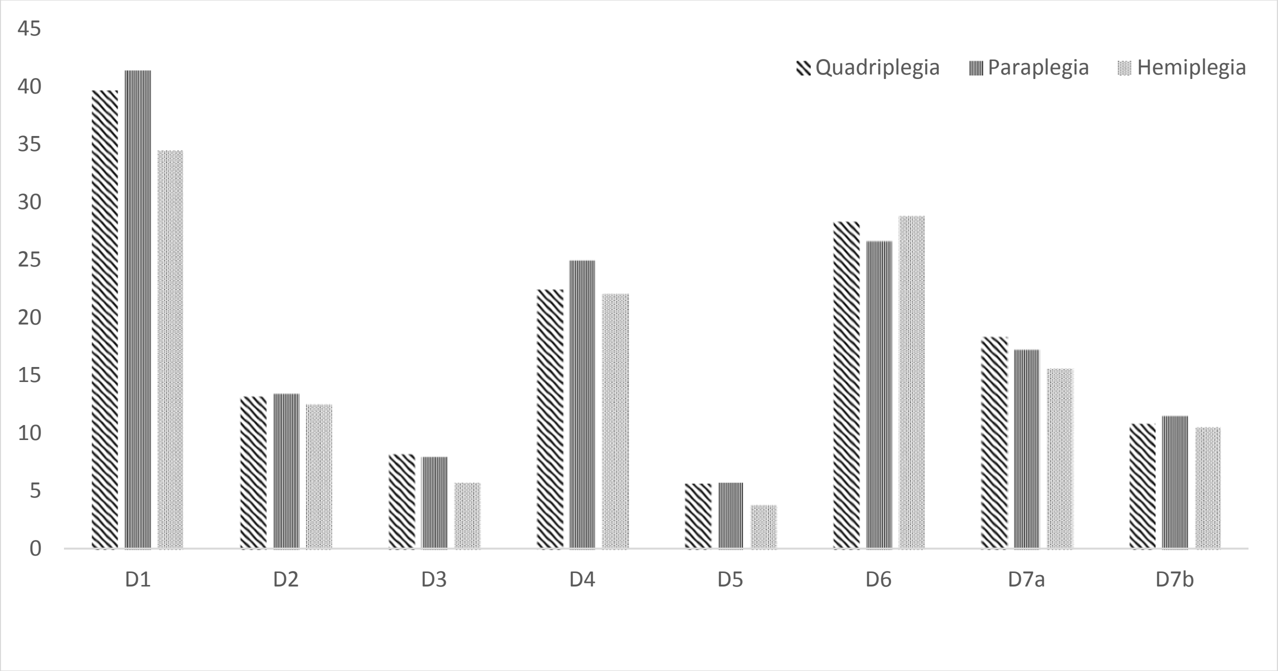

Figure 4.3: Mean percentage scores across the domains for children with different topography.

V. Comparison of QoL between the age groups

Shapiro Wilk test was carried out to check for normality for all the domains across the three age groups viz., 4-7 years, 7.1-10 years and 10.1-12 years. There were 21 children in group 1 (4-7 years), 9 children in group 2 (7.1-10 years) and 16 children in group 3 (10.1-12 years). It was found that in the 4-7 years age group all the domains were normally distributed ($p>0.05$). In the other two age groups all the domains also followed normal distribution ($p>0.05$) except D5 in the age group 2 and D2, D5 and D7b in the age group 3. The mean percentage scores and standard deviation obtained across the three age groups have been depicted in table 4.7 and graphically in figure 4.4. The mean scores of 4-7 years age group was higher followed by 10.1-12 age group. The 7.1-10 year age group had the least total QoL scores which indicated poor

QoL in these children. MANOVA was carried out for domains which were normally distributed i.e., D1, D3, D4, D6, and D7a across the three groups. It was found that there was no statistically significant difference across age groups ($p>0.05$) in the domains D1, D3, D4, D6, and D7a. The F and p values have been depicted in the table 4.8. Since the overall QoL of all domains was following normal distribution, Test of Oneway ANOVA was also carried out to compare age groups. The results revealed no statistically significant difference between ages with regard to overall total scores [F (2, 43=0.80, $p>0.05$].

Further, for the domains which were not distributed normally Kruskalwallis test was carried out for the domains (D2, D5, D7b) and it was found that across age, a significant difference was present only for domain D5 (χ^2 (2) =6.665, $p < 0.036$)and there was no significant difference in the other two domains. Mann-whitney test was done to find the significance across age group in D5 which revealed that between the age group 1 and 2 there was no significant difference present ($p>0.05$) however a significant difference was obtained for the age groups between 1 and 3 ($z=2.22$, p=<0.05) and age group 2 and 3 ($z=2.099$, $p<0.05$).

Table 4.7:

Mean percentage and standard deviation (SD) values of the three age groups for the scores of QoL on all the domains.

Domain	**N**	**4-7 years**	**N**	**7.1-10 years**	**N**	**10.1-12 years**
D1	21	68.64±14.07	9	60.36±15.52	16	65.10±18.51
D2	21	63.33±14.26	9	64.44±17.03	16	67.81±24.29
D3	21	65.47±15.43	9	55.55±19.09	16	66.14±22.66
D4	21	53.13±14.84	9	50.75±18.22	16	52.12±18.60
D5	21	40.87±23.99	9	31.48±31.11	16	58.33±21.29
D6	21	61.00±14.77	9	53.93±14.10	16	57.81±15.93
D7a	21	60.37±14.89	9	63.88±10.63	16	62.72±17.05
D7b	21	55.47±18.77	9	49.44±13.57	16	55.94±16.75
Total	21	60.26±7.46	9	55.34±8.43	16	60.24±13.00

Values are given as Mean±SD; D1=Family & Friends, D2=Participation, D3=Communication, D4=Health, D5=Special Equipment, D6=Pain & Bother, D7a=Access to services, D7b= About Yourself.

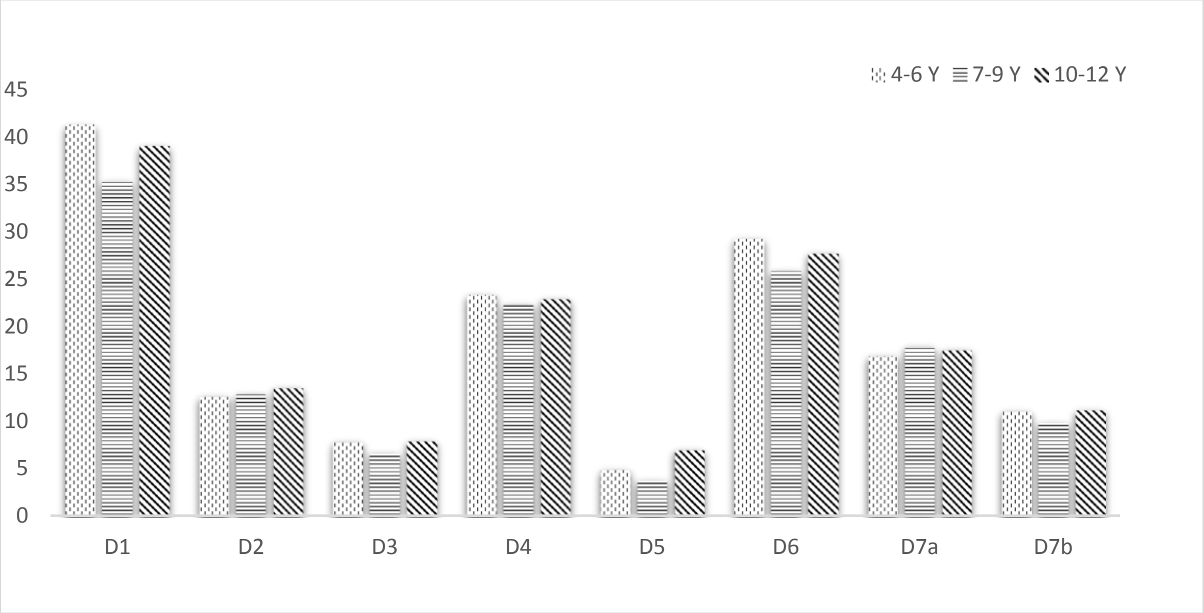

Figure 4.4. Mean scores of QoL across the three age groups in children with CP on all domains.

Table 4.8:
Fand p values of between subject effects across the domains.

Domain	F(2,43)	P value
D1	1.09	0.34
D3	1.06	0.35
D4	0.06	0.93
D6	0.72	0.49
D7a	0.21	0.81

D1=Family & Friends, D2=Participation, D3=Communication, D4=Health, D5=Special Equipment, D6=Pain & Bother, D7a=Access to services, D7b= About Yourself

VI. Comparison of QoL across gender

The mean and standard deviation values for both the gender within each age groups were computed using descriptive statistics. The mean and standard deviation obtained have been depicted in table 4.9, 4.10 and 4.11. The mean percentage obtained have also been depicted in table 4.12. The total mean scores of QoL were slightly higher for the females than for males in the 4-7 year and 10.1-12 years age group. However the mean percentage scores were higher for males than for females in the 7.1-10 years age group. The mean scores on all the domains for males and females in all the age groups were comparable. The total mean percentage was highest for females when compared to males when the different age groups are combined into one group. To check whether a significant difference existed between the three age groups, Mann-Whitney test was carried out and the results revealed no statistical significance ($p>0.05$) across gender in all the three age groups indicating quality of life to be equivalent in all the three groups irrespective of gender. The /z/ values have also been depicted in table 4.9, 4.10 and 4.11 for the three age groups.

Table 4.9:

Mean and standard deviation (SD) and /z/ values of QoL scores of both gender in the 4-7 year age group.

Domain	**N**	**Male**	**N**	**Female**	**/z/**
D1	14	40.28±8.36	7	43.28±9.01	0.59
D2	14	12.71±2.75	7	12.57±3.25	0
D3	14	8.00±1.96	7	7.57±1.71	0.34
D4	14	22.57±5.07	7	25.00±9.03	0.59
D5	14	4.85±2.90	7	5.00±3.055	0.11
D6	14	28.50±7.58	7	30.85±6.22	0.75
D7a	14	17.42±4.55	7	15.86±3.33	0.87
D7b	14	10.93±3.93	7	11.43±3.64	0.30
Total	14	145.28±17.82	7	151.57±20.54	0.63

Values are given as Mean±SD, D1=Family & Friends, D2=Participation, D3=Communication, D4=Health, D5=Special Equipment, D6=Pain & Bother, D7a=Access to services, D7b= About Yourself.

Table: 4.10:

Mean and deviation (SD) and |z| values of QoL of both gender in the 7.1-10 years age group.

Domain	**N**	**Male**	**N**	**Female**	**/z/**
D1	4	33.75±4.11	5	36.60±16.19	1.47
D2	4	11.25±2.75	5	14.20±3.56	1.35
D3	4	7.75±2.21	5	5.80±2.16	1.37
D4	4	26.75±8.01	5	18.80±6.72	1.49
D5	4	3.25±3.77	5	4.20±4.08	0.39
D6	4	28.00±7.11	5	24.20±6.76	0.25
D7a	4	18.00±1.41	5	17.80±4.02	0.25
D7b	4	10.25±1.25	5	9.60±3.64	1.36
Total	4	139.0±11.40	5	133.20±27.82	0.49

Values are given as Mean±SD, D1=Family & Friends, D2=Participation, D3=Communication, D4=Health, D5=Special Equipment, D6=Pain & Bother, D7a=Access to services, D7b= About Yourself.

Table: 4.11:

Mean and standard deviation (SD) and |z| values of QoL of both gender in the 10.1-12 years age group.

Domain	**N**	**Male**	**N**	**Female**	**/z/**
D1	11	36.72±11.70	5	44.20±8.49	0.90
D2	11	13.72±55	5	13.20± 7.52	0.63
D3	11	7.81±2.78	5	8.20±2.86	0
D4	11	23.81±6.53	5	21.0±11.72	0.34
D5	11	7.0±3.0	5	7.00±1.41	0.52
D6	11	29.18±8.17	5	24.60±5.85	1.19
D7a	11	16.45±4.41	5	20.00±5.09	1.14
D7b	11	11.18±3.68	5	11.20±2.86	0.22
Total	11	145.90±29.17	5	149.40±40.45	0.06

Total Values are given as Mean±SD; D1=Family & Friends, D2=Participation, D3=Communication, D4=Health, D5=Special Equipment, D6=Pain & Bother, D7a=Access to services, D7b= About Yourself.

Table 4.12:

Mean percentage and standard deviation (SD) values of QoL across gender in all domains.

Domain	**N**	**Male**	**N**	**Female**
D1	29	63.15±15.78	17	70.29±15.73
D2	29	*64.48*±15.43	17	66.17±23.35
D3	29	65.80±18.81	17	60.29±19.21
D4	*29*	53.67±13.65	17	49.99±20.79
D5	29	45.40±26.96	17	44.60±25.67
D6	29	59.77±15.61	17	56.37±14.02
D7a	29	61.20±14.77	17	63.02±15.09
D7b	29	54.65±17.52	17	54.12±16.60
Total	29	145±17.82	17	151.57±20.54

Values are given as Mean±SD; D1=Family & Friends, D2=Participation, D3=Communication, D4=Health, D5=Special Equipment, D6=Pain & Bother, D7a=Access to services, D7b= About Yourself.

VII. Comparison of QoL in children with and without associated problems

The effect of associated problems on the QoL was compared among children with no associated problem (NA), with 1 associated problem (1A) and more than one (multiple) associated problems (MA). There were 11 children with no associated problems, 12 children with one associated problem and 23 children with multiple associated problems. The associated problems seen in these children were mental retardation, hearing impairment, visual impairment and seizure disorder. Shapiro wilk test of normality was carried out and it was found that the data was not normally distributed. The mean percentage and standard deviation obtained have been depicted in table 4.13. On comparison, it was seen that the total mean percentage scores for those who had no associated problems were higher when compared to those who had one or more than one associated problems which indicated better QoL in those children with no associated problems. When the mean scores of all domains were compared between the three groups, it was seen that the mean percentage scores of all domains except D2, D3 and D7a was higher for the group with no associated problem. To check whether a significant difference existed between the three groups, Kruskal-Wallis test was carried out. The results revealed no statistically significant difference ($p>0.005$). The values have been depicted in table 4.14. The mean scores obtained across the domains of the three groups have been depicted in figure 4.5.

Table 4.13:

Mean percentage and standard deviation (SD) values for the scores of QoL in all the domains for children with no, one or more than one associated problems.

Domain	**N**	**NA**	**N**	**1A**	**N**	**MA**
D1	11	70.14±12.21	12	68.19±15.59	23	62.45±17.55
D2	11	65.90±24.57	12	74.16±12.21	23	60.00±16.71
D3	11	65.14±22.91	12	71.52±18.95	23	59.05±16.07
D4	11	60.32±24.42	12	54.35±14.32	23	47.42±11.20
D5	11	52.31±16.52	12	47.72±26.63	23	39.58±27.32
D6	11	58.89±17.08	12	57.46±16.22	23	58.87±13.92
D7a	11	62.65±15.99	12	65.47±14.86	23	59.62±14.34
D7b	11	60.90±18.14	12	59.16±19.75	23	48.91±13.48
Total	11	62.60±14.11	12	61.77±8.47	23	56.40±7.45

Values are given as Mean±SD; D1=Family & Friends, D2=Participation, D3=Communication, D4=Health, D5=Special Equipment, D6=Pain & Bother, D7a=Access to services, D7b= About Yourself.

Table 4.14:

Values of Kruskalwalli test for the scores of QoL on all the domains for children with no, one or more than one associated problems.

Domain	$\chi^{2(2)}$	**P value**
D1	1.38	0.50
D2	5.71	0.06
D3	3.39	0.18
D4	4.54	0.10
D5	0.65	0.72
D6	0.11	0.94
D7a	1.04	0.23
D7b	4.29	0.59

D1=Family & Friends, D2=Participation, D3=Communication, D4=Health, D5=Special Equipment, D6=Pain & Bother, D7a=Access to services, D7b= About Yourself.

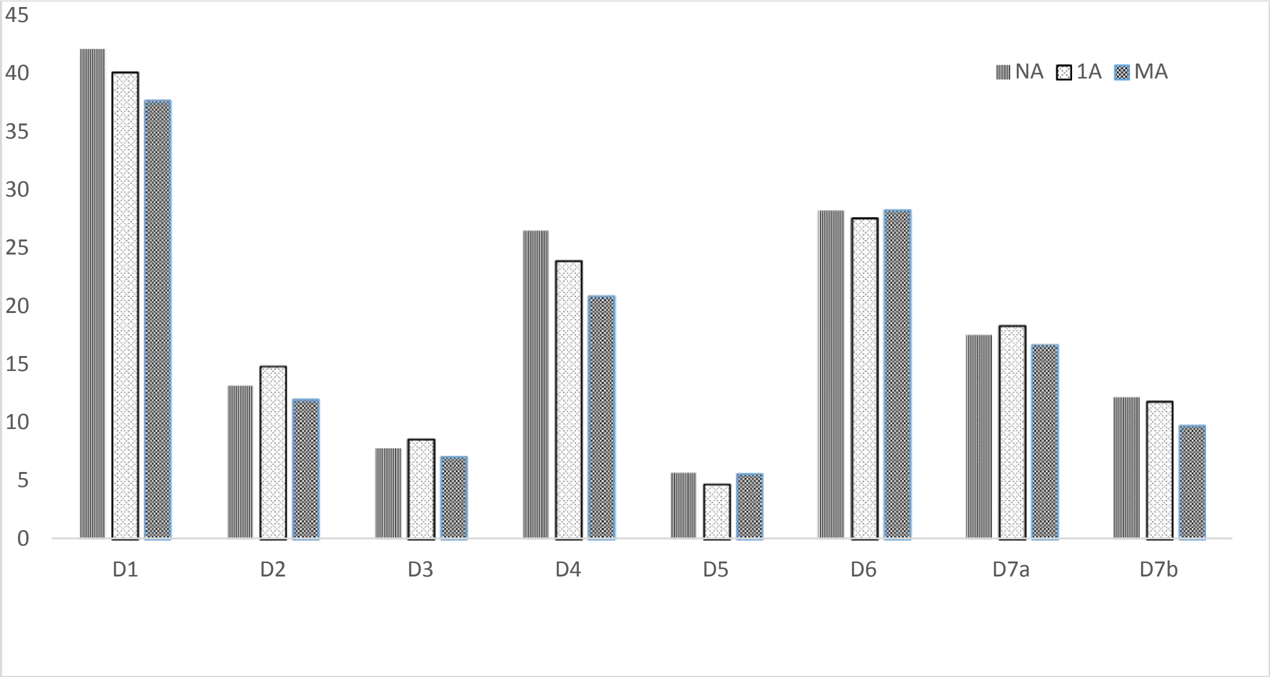

Figure 4.5. Mean scores of associated problems across the domains.

VIII. Comparison of QoL in children who had undergone intervention for a duration of less than 1 year to those with intervention duration of more than 1 year.

The influence of intervention on the QoL scores as obtained on the questionnaire was assessed. There were 19 children with CP who had undergone intervention for less than 1 year (L1Y) and 27 children with CP who had undergone intervention for more than 1 year (M1Y). The intervention consisted of physiotherapy, occupational therapy, speech and language therapy, medical treatment and pharmacological treatment. Shapiro wilk test was carried to check for normality and it was found that the data was not normally distributed. The mean percentage and standard deviation obtained have been depicted in table 4.15. On comparison, it was seen that the scores for those who had attended intervention for a duration of M1Y were higher when compared to those who had attended lesser L1Y indicating that greater the duration of intervention, better is the QoL. Moreover the mean scores of all the domains was greater for those who attended intervention for more than a year except D6 i.e., Pain and Bother. To check whether a significant difference existed between the two groups, Mann-Whitney test was used. The results revealed no statistically significant difference ($p>0.05$). The $|z|$ values have been depicted in table 4.15. The mean of the scores obtained across the domains of the two durations of intervention have been depicted in figure 4.6.

Table 4.15:

Mean percentage and standard deviation (SD) and |z| values for the scores of QoL on all the domains.

Subdomain	**N**	**<1 year**	**N**	**>1 year**	**/z/ value**
D1	19	63.32±19.56	27	67.53±13.00	1.08
D2	19	61.05±21.44	27	67.96±15.95	1.05
D3	19	58.33±20.22	27	67.59±17.35	1.59
D4	19	50.35±16.69	27	53.69±16.58	1.67
D5	19	35.96±29.66	27	51.54±21.81	2.09
D6	19	59.75±17.22	27	57.63±13.45	0.40.
D7a	19	59.77±15.83	27	63.35±14.06	0.84.
D7b	19	52.10±13.77	27	56.11±19.03	0.52.
Total	19	57.03±11.55	27	60.87±8.37	1.29.

Values are given as Mean±SD; *D1=Family & Friends, D2=Participation, D3=Communication, D4=Health, D5=Special Equipment, D6=Pain & Bother, D7a=Access to services, D7b= About Yourself.*

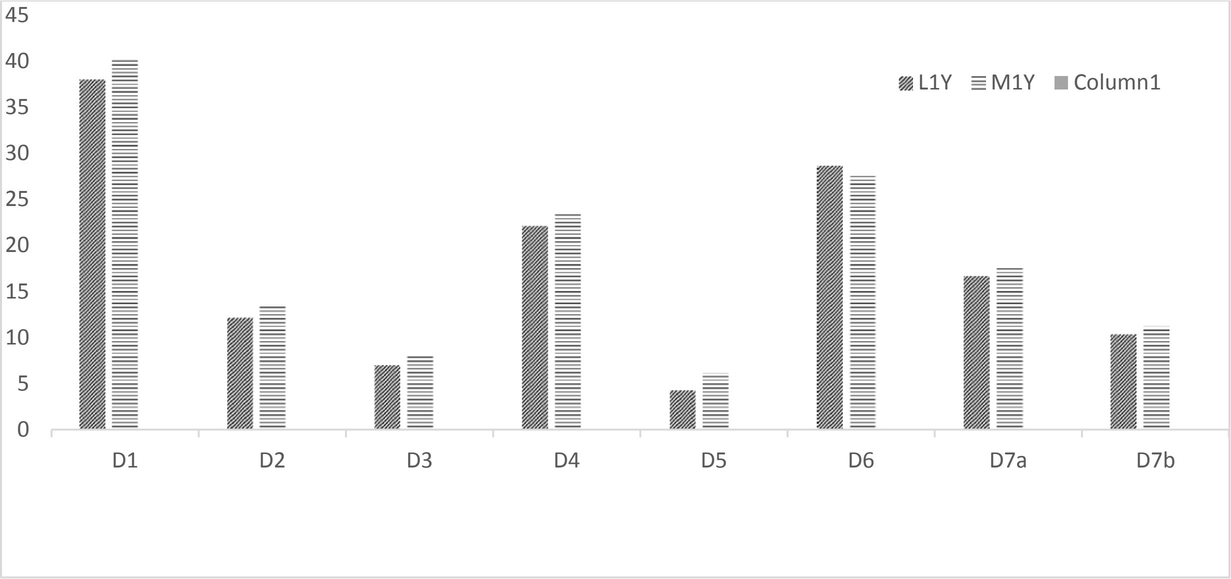

Figure 4.6. Mean scores of duration of intervention across the domains in children with CP.

In sum the results of the present study indicated that the QoL was mildly affected in all the domains except domain five (special equipment) which was moderately affected. The alpha values obtained were also high indicating good reliability. On comparison of QoL scores across different severity of CP it was seen that the mean scores of QoL was highest for children in the level I when compared to other groups indicating better QoL in children with less severity. The mean scores were higher for children with paraplegia when compared to the other two groups (hemiplegia and quadriplegia) indicating better QoL in children with paraplegia. The mean scores were the least for group 3 (hemiplegia) indicating poor QoL. On comparison of the mean scores across three age groups it was found that the mean scores were higher for the 4-7 year age group followed by 10.1-12 age group and the 7.1-10 year age group. Although the total mean scores was higher for females when compared to males, there was no significant difference between gender indicating QoL to be equivalent in both the groups.

It was seen that the QoL for those who had no associated problem was higher when compared to those who had one or more than one associated problems which indicated better QoL in those with no associated problems. However there was no significant difference found between the three groups. The QoL was higher for those who had attended intervention for a duration of more than one year when compared to those who had attended less than one year indicating that greater the duration of intervention, better was the QoL. However there was no significant difference found between the groups.

Chapter 5

Discussion

The present study aimed at assessing the quality of life (QoL) of children with cerebral palsy (CP) in the age range of 4-12 years across different domains such as Family and Friends, Participation, Communication, Health, Special Equipment, Pain and Bother and Access to Services. The specific objectives of this study were to compare the domain wise score of QoL obtained on the questionnaire, to compare between QoL scores and severity of CP, to compare QoL between different topography viz., quadriplegia, paraplegia, hemiplegia, to compare QoL between different age groups viz., 4-7 years, 7.1-10 years and 10.1-12 years, to compare the QoL across gender, to assess the effects of associated problems on QoL and to assess the influence of intervention on QoL. The study revealed some interesting findings.

First, the total QoL scores obtained for all the participants was59.29, (SD=9.87)which indicated that children with CP had mildly affected QoL if interpreted based on the Lifestyle Assessment Scale (LAS-CP Mackie, Jessen, & Jarvis, 1998). The comparison of scores obtained across the different domains i.e., family & friends, participation, communication, health, special equipment, pain and bother, access to services, about yourself, indicated that the mean percentage scores of QoL was highest in the domain 1 (Family and Friends, 65.79%) and the lowest for domain 5 (Special equipment, 45.11%). Based on the Lifestyle Assessment Scale, it can be interpreted that the QoL was mildly affected in all the domains (52-65%) and was moderately affected (45%) in domain 5.

The finding that QoL was mildly affected in all children with CP could be because of the fact that although CP affects the motor, speech & language, self-help and play domains to a large extent, the children were under intervention. The motor issues affect their mobility and activities of daily living and their speech language deficits affect their communication and social skills. The higher score on domain 1 (family and friends) could be due to the increased level of acceptance and support provided by the family members and by other children outside preschool or school. The lower score on domain 5 (special equipment) could be attributed to varied levels of socio economic status (low and high) of the parents/caregivers who were included in the study, high cost of equipments, limited awareness and knowledge and regarding the available sophisticated equipments which could lead to reduced accessibility to equipments. Hence from the above findings it can be inferred that children with CP have difficulties in all the domains such as overall social wellbeing and acceptance, participation and physical health, functioning, emotional wellbeing and self-esteem, pain and impact of disability

The findings of the present study is in consensus with the studies carried out by Liptak et al., (2001), Wake et al., (2003), Dickinson et al., (2007), Remo et al (2008), Arnaud et al., (2008), Thurston et al., (2010), Tella et al., (2011), Badiya et al., (2014) which also revealed that children with CP had poor QoL. Wake et al., (2003) also revealed that children with severe CP had the poorest physical health, but psychosocial health and emotional impact on parents were similar for mild and severe CP. Dobhal et al., (2014) found that 9% of the children with CP had good, 24% had mildly affected, 37% had moderately affected and 30 % had severely affected HRQoL. They also found that the physical independence, mobility and social integration dimensions were much more severely affected than the clinical and economic burden and schooling dimensions and concluded that HRQoL is affected in most children with CP. However in the present study it was found that in all children QoL was mildly affected.

With regard to the different domains, Elizabeth (2010) revealed that the domains social well-being, emotional well-being, and functioning obtained the highest scores, while the domain of pain and impact of disability, participation and physical health had the lowest scores. However in the present study, it was found that the children obtained lower scores on the domain on special equipment compared to the other domains. This could be due to the differences in the participant group.

Bjornson et al., (2008), however revealed that children with CP had similar QoL to children in the general population in all domains except schooling. Sanna et al., (2013) also revealed that the overall QoL was good in Finnish children with CP, however the correlation of QoL scores between the caregivers and children was good except in the domain of pain and the impact of disability. These results are not in agreement with the results of the present study. This also could be attributed to the differences in the ethnic background of the participants and other participant related variables.

It was also found that parental stress did not influence the QoL scores obtained on first six domains since no correlation was found on the scores obtained on the stress questionnaire and the total of QoL scores obtained on the first six domains. However QoL scores and parental stress scores was found to be significantly correlated only for domain 7. Since domain 7 involved questions about the caregiver viz., (about their physical health, work situation, financial situation, how happy they were and availability/time for child care etc,) it showed a negative correlation i.e., higher stress with low QoL. This could also indicate that the parental responses were reliable and their rating on the first six domains was not influenced by their own stress levels.

The study is in contradiction to the study by Koning et al., (2008) who compared the reports of parents and professionals of the QoL in 8-12 years children with CP. Their study revealed that parents with high level of stress had poor Qol and influenced parent reports of child QoL compared to professional reports. The study by Colver et al., (2015) also revealed that the child psychological problems and parenting stress in childhood could predict small reductions in QoL. Arnaud et al., (2008) also revealed that parents with higher level of stress were found to have poorer QoL in all domains which suggests that parent’s report of the QoL may be influenced by the factors other than the severity of the child’s impairment.

Moreover the first six domains (D1-D6) and caregivers section was found to be significantly correlated with D7. This could be attributed due to the increase in the acceptance of the children with CP irrespective of their problem and high parental motivation to provide all possible rehabilitation services for their children, which indicated that better the extent of different intervention/treatments provided to the children with CP such as access to medical treatment, physiotherapy, speech therapy, occupational therapy, surgical care etc., better was the child’s participation in their community. This could also indicated that access to different possible treatments facilitated communication with people around them and also the way other people communicate with them using any means of communication. The better the financial and work situations, health condition and the availability (time) for child care, better would be the QoL of the children with CP. These findings are in consensus with the study by Sanna et al., (2013) who also reported good correlation of QoL scores between the caregiver and children except in the domain of pain and impact of disability.

Secondly, it was found that the mean scores of QoL were higher for children with less severity level and lower for greater severity levels indicating better quality of life in children with less severity level. However there was no statistically significant difference found between QoL scores and severity levels. Also the participants in the level V had better QoL scores than the participants in level II, III and IV. The lack of significant difference could be attributed to unequal sample size in each severity level. This could be also possibly be due to the intensive intervention services provided and greater care taken by the parents/caregivers considering the severity of the condition.

On similar lines Arnaud et al., (2008) reported that greater severity was not always related to poor QoL. Another study by Tessier et al., (2014) also have found that there was no significant association found between GMFCS level and QoL. However the study by Liptak et al., (2001) is not in agreement with the present study since they also reported that in children with GMFCS level V who used feeding tube required more health care resources, used most medicines, had greater respiratory problems and had the lowest global health scores. Wake et al., (2003) also reported that children with severe CP had the poorest physical health, but psychosocial health and emotional impact on parents were similar for mild and severe CP showing that this should not be assumed to be less prevalent when CP is mild. Tella et al., (2011) reported severity of the CP had a negative impact on physical function, social role/behaviour, parenting impact (time/ emotion), children’s health and their psychosocial function. The present study also showed that the participants with the least severity did not obtain the maximum scores on participation, communication, special equipment and access to services. This could be attributed to the high level of parental expectations considering the milder nature of the severity. Colver et al., (2015) also found that severity of impairment was significantly associated with low QoL on three domains i.e., (Moods and emotions, Autonomy, and Social support and peers).

When the scores on the questionnaire were compared across three groups of children having quadriplegia, paraplegia and hemiplegia it was found that children with paraplegia had the highest scores on QoL when compared to hemiplegics and quadriplegics indicating better QoL in children with paraplegic condition. This could be attributed to the motor deficits. In paraplegics only the lower limbs are only affected with writing and other functions being spared or minimally affected. However in hemiplegics and quadriplegics all these functions are affected leading to poor QoL. Children with hemiplegia scored the least which indicated poor QoL in these children. This could be attributed to high expectation of improvement by the parents/caregivers compared to the quadriplegics. However the group with paraplegia had higher QoL scores on all domains except D3 (communication), D6 (Pain & Bother) and D7a (Access to services). According to Dickinson et al., (2007) pain was common in children with CP and was associated with lower QoL on all domains. Badiya et al., (2014) also reported that pain was present in 51% of the children with CP which lead to poor QoL scores. Schenider and Majnemar (2013) also reported that pain had a high prevalence in children with CP and had an impact on QoL. Bjornson et al., (2008) reported that pain was present in all severities of children with CP. With regard to access to services possibly, the children were not provided the intervention services for a longer duration considering the nature of deficits in them compared to the more severe deficits in hemi and quadriplegics. The deprivation in communication in children with paraplegic condition can be attributed to pain related factors and inaccessibility to services. It was also found that scores on D3 (communication) and D7a (Access to services) in the group with quadriplegia were high which could be due to the attempts made by the caregivers to seek various services such as medical treatment, access to therapy, extra help at preschool and exposure to various other communication services including the augmentative and alternative communication services. This could have resulted in better QoL. There was statistically significant difference found only in the domain 3 (communication) across the quadriplegics and hemiplegics indicating better quality of life in children with quadriplegia. This could be possibly due to the exposure of children with quadriplegia to augmentative and alternative communication approaches leading to improved communication and better QoL. This could also be due to the adaptation in the parent’s perceptions about their child’s QoL. Scores in children with Hemiplegia could be low in comparison to quadriplegics due to the higher level of parental expectations that the child would be able to communicate through speech and therefore the increased emphasis on speech. However there was no overall statistically significant difference found between the three groups with respect to topography indicating that topography does not have a major effect on the QoL of children with CP. The study by Remo et al., (2008) is in consensus with the present study since it also revealed that children with hemiplegia experience reduced QoL and self-concept compared to typically developing peers. A study by

Dobhal et al., (2014) also reported that subjects with quadriplegic CP had mildly affected QoL.

The comparison of QoL across the three age groups viz., 4-7 years (n=21), 7.1-10 years (n=9) and 10.1-12 years (n=16) revealed higher scores in 4-7 years age group, followed by 10.1-12 age group and the least score for 7.1-10 year age group indicating better QoL in the age group 4-7 years when compared to both the other groups. This result could be due to several factors such as increasing maturation levels, intensive intervention, increased participation from the parents, increased motivation and stimulation level in these children at an early age. There was a reduction seen in the QoL scores in 7.1-10 years which could be attributed to certain factors such as schooling. At this age the children are enrolled to a school, their performance are mostly compared with that of the peers leading to increased expectations and pressure from the parents. This could result in a mismatch between the demands placed on the child and the capacity of the child in terms of academic, motor and sensory abilities. Schooling could also possibly hamper or result in discontinuity of the intervention undertaken by the children such as physiotherapy, speech therapy, occupational etc since such facilities are not available in most schools and the parent may not get adequate time to take their child for such services after school hours. An increase in the QoL scores again in the 10.1-12 years could be possibly due to the adaptation of the participants to their own problem and better realization of the abilities which in turn help them in channelize their energy towards carrying out the tasks they are capable of. Further, it was also found that there was a statistically significant difference between group 1 (4-7 years) and group 3 (10.1-12 years) in domain 5 (Special Equipment) which indicated that with advancing age, there was increased awareness and usage of special equipments such as wheel chairs, walkers etc. which in turn leads to an improvement seen in the mobility of the children with CP.

In consensus with the present study, Tessier et al., (2014) also revealed that there was no significant association between age and psychosocial QoL domain viz., (social well-being and acceptance, emotional well-being and self-esteem. Similar findings were revealed by Elizabeth et al., (2010) who reported that children in the age range between 9-11 years performed better in all domains when compared to 12 & 13. Tella et al., (2011) also revealed that increasing age and severity of the CP had a negative impact on physical function, social role/behaviour, parenting impact (time/ emotion), children's health and their psychosocial function due to the subject's physical condition interfering with their personal and social activities. This may indicate limitations in school work, social activities, and friendships. Thurston et al., (2010) also reported QoL scores decreased with increase in age.

When the QoL was compared across gender, it was observed that the scores of QoL were slightly higher for the females than for males in the 4-7 year and 10.1-12 years age group whereas the scores were slightly higher for males than for females in the 7.1-10 years age group. However the present study did not reveal a significant difference across gender in the three age groups. This indicated that irrespective of the gender, all participants were treated equally and given equal opportunities to facilitate an improvement in the QoL. This could be attributed to the nature and unequal sample size considered limiting the power of the study to demonstrate differences across gender**.**

Our study is in consensus with the studies carried out by Melisa et al., (2009), and Tessier et al., (2014) and Elizabeth et al., (2013) which revealed that between both gender groups there was no significant difference. However a study by Dobhal et al., (2014) revealed that Lifestyle Assessment Score was significantly greater in boys when compared to girls indicating moderately affected QoL in boys in the age range 3-10 years due to difference in severity, psychosocial factors and availability of the health care services. This could be because of the difference in the age group and the tool used to assess QoL.

An attempt was made to compare the effect of associated problems on the QoL and it was found that scores of QoL were higher for those who had no associated problems when compared to those who had one or more than one associated problems. This indicated better QoL in those children with no associated problems. However children with no associated problems were found to have low scores on three domains i.e., D2 (Participation), D3 (Communication), and D7a (Access to services). This indicated that participation, communication and access to Services could be important factors influencing the QoL in children with CP. This also indicated that even with no associated factors being present, the CP itself causes some participation and communication restriction.

During administration of the questionnaire it was also noticed that the participants were not able to gain access to services either from the physiotherapy, speech therapy and occupational therapy which could have a negative impact in the communication ability of the child and thereby hindering their participation in the environment. However there was no statistically significant difference found across all the three groups.

The findings of this study is in agreement of the study by Thurston et al., (2010) which revealed that QoL was lower for children with multi diagnosis group when compared to children with single disorders group and healthy children. Dobhal et al., (2014) reported that children with seizure disorder, visual problems, cognitive deficits and feeding problems had mildly affected QoL which is in contrast to the results of the present study. This could be due to the difference in the tool considered to assess the QoL.

The influence of intervention on QoL in children with CP was assessed and it was seen that the total and domain wise mean scores for those who had attended intervention for a duration of more than 1 year (M1Y) were higher when compared to those who had attended lesser than 1 year (L1Y) indicating the fact that greater the duration of intervention, better was the QoL. However children who had attended intervention for more than a year scored low in the domain of pain and Bother. This finding could possibly indicate that pain and bother was an important factor which could persist even after years of intervention having a negative impact on the QoL in children with CP and therefore should be considered during management. On similar lines to our study Elbasan et al., (2013) also reported that children with CP experience more pain and discomfort. However, if early rehabilitation is provided, the pain can be kept under control resulting in increased QoL.

Chapter 6

Summary and Conclusions

A look into the literature revealed that varied methods using different questionnaires have been employed to assess the HRQoL in children with cerebral palsy (CP) in different countries across the globe. The domains of HRQoL studied are also different in different studies. The findings from these studies indicate that the relationship between the QoL of children with CP and their disability is not yet clear. This is because of the conflicting results obtained across studies. These studies have come to different conclusions regarding the impact of CP on the well-being of these children with respect to different domains assessed. Studies by Liptak et al., (2001); Arnaud et al., (2008); Elizabeth, (2010); Tella et al., (2011); Abanto et al., (2012); Badiya et al., (2014); and Tessier et al., (2014) have reported that children with CP have poor HRQoL. However other studies by Bjornson et al., (2007); and Sanna et al., (2013) have reported that these children have good HRQoL. Certain studies have reported that not all domains are affected in children with CP. Further. HRQoL in the children with CP in comparison with other developmental disabilities, is still understudied, with scarce research assessing self-reported HRQoL and its links with other psychological variables.

Although studies have investigated the QoL, most of the studies have not associated it with variables such as type of CP and the topographical distribution. QoL could vary with whether the child is spastic or dyskinetic, quadriplegic or monoplegic. Very few studies have addressed the correlation between comorbidities and HRQoL. Moreover the HRQoL can also vary with the age of the child and gender. This has also been explored by a limited number of studies (Elizabeth et al., 2010; Tella et al., 2011; Tessier et al., 2014) which have again yielded conflicting results. Further the extent of rehabilitation services received by the child with CP also can impact HRQoL. Further QoL needs to be measured since such studies provide guidelines for professionals in implementing effective rehabilitation programs to reduce the level of strain and increase the HRQoL, self- care and social function of children with CP. Since the goal of most interventions for these children is to preserve or improve QoL, these outcomes must be included in clinical trials of these interventions whenever possible. Keeping this in view, a need was felt to assess the QoL in children with CP.

Hence the present study was aimed at assessing quality of life in children with CP in the age range of 4-12 years with regard to different domains using the Cerebral Palsy Quality of Life Questionnaire. The study was undertaken in three phases which are adaptation of the quality of life questionnaire to the Indian context, administration of the questionnaire on mothers/caregivers of children with cerebral palsy and assessment of test-retest reliability. In the initial phase the preliminary version of a Cerebral Palsy Quality of Life Questionnaire for children (CP QOL-Child, Version 2, Waters, Davis, & Boyd, 2013, primary caregiver questionnaire 4-12 years) was adapted for the assessment of perspectives of the parents/caregivers regarding the difficulties faced by their children with cerebral palsy. Each statement was assessed for its usefulness in the Indian context. The statements in this questionnaire focused on the physical, health, social, academic, financial problems faced and the impact of these on the day to day activities and on the overall quality of life of the child. The statements were grouped under seven domains such as Family and Friends, Participation, Communication, Health, Special Equipment, Pain and Bother, and Access to Services. A five point rating scale to assess the problems objectively was also prepared on the lines of the original questionnaire to rate the responses obtained from the parents in order to obtain an objective score.

The content validity of the preliminary version of the Cerebral Palsy Quality of Life questionnaire and the rating scale was assessed by obtaining the feedback from three experienced speech-language pathologists. They were asked to judge the appropriateness of the items included and the rating scale used. The feedback was collected using a 3 point rating scale ranging from the contents are not very valid (score 0) to all the contents are valid (score 2). Following content validation the questionnaire which contained 66 items were reduced to 61 items. The content and the structure of the sentences were also modified as per the suggestions given by the professionals. The final English version of the CP QOL- CHILD was translated into Kannada and Malayalam languages.

A pilot study was carried out in which this questionnaire was administered on three parents/caregivers of children with cerebral palsy in the different age groups between 4-12 years to verify if all the items were understandable and satisfactory. Children with different types of cerebral palsy were included. The responses obtained were documented and grouped under different domains. After the pilot study it was found that there was a need to simplify few questions and include examples under a few items in the questionnaire for better understanding of the questions by the parents/caregivers.

The final version of the questionnaire was prepared after the pilot study. The final form of the questionnaire had a total of 61 items with 15 items in Family and Friends, 5 items in Participation, 3 items in Communication, 11 items in Health, 3 items in Special

Equipment, 12 items in Pain and Bother, and 12 items in Access to Services. This was administered on the parents of 46 children with cerebral palsy in the age range of 4-12 years.

A total of 46 children with CP (17 females and 29 males) between the age-range of 4-12 years who reported to the Department of Clinical Services, AIISH, Mysore and who had Kannada and Malayalam as their native language were considered for this study. They were diagnosed as having Delayed speech and language with CP by a qualified team of professionals including the speech and language pathologist, physiotherapist, paediatrician and a clinical psychologist. They were grouped based on age in which they were assigned under three groups (4-6, 7-9 and 10-12 age range), gender, topographical distribution, duration of intervention undertaken and associated problems. There were 21 children in the age group (4-7 years), 9 in (7.1-10 years) and 16 in (10.1-12 years). There were 37 children with spastic type of CP, 8 with flaccid type of CP and 1 with dystonic type of CP. There were 23 children with quadriplegia, 11 with paraplegia, 9 with hemiplegia, 2 with triplegia, 1 with monoplegia. All the participants included were enrolled in an intervention program. 27 participants had attended speech language intervention and physio/occupational intervention for a duration of greater than one year and 19 children attended intervention for a duration of less than a year. Some children with CP had no associated problems while others had a few associated problem such as the visual impairment, mental retardation, seizure disorder, etc. There were 11 children who had no associated problems, 12 who had only one associated problems and 23 who had more than one associated problems. The socioeconomic status scale developed by Venkatesan (2009) was used to assess the socio economic status of participants. The severity of motor disability was also assessed and classified using the Gross Motor Function Classification System (GMFCS) ranging from I to V severity groups. All ethical standards were met for participant selection and their participation. Prior to testing, a written consent as obtained from the parents of the participants after explaining the purpose of the study.

The testing was carried out in a relatively noise free environment with minimum distractions. A rapport was built with the mother/caregiver and the purpose of the study was explained to them. They were made to sit individually and fill the final version of the cerebral palsy quality of life questionnaire. Additional clarification was provided to the parents wherever necessary. The responses obtained from the parents/caregivers were documented based on the rating scale. The time taken to administer the questionnaire was approximately 35 minutes. Finally to assess the test-retest reliability, the questionnaire was administered again on 10 of the participant sample after a duration of one week.

The results of the present study indicated that the QoL was mildly affected in all the domains except domain five which was moderately affected. On comparison of QoL scores across different severity of CP it was seen that the mean scores were highest for children in the level I indicating better QoL in children with less severity. The mean scores were higher for children with paraplegia when compared to the other two groups (hemiplegia and quadriplegia) indicating better QoL in children with paraplegia. The mean scores were the least for group 3 (hemiplegia) indicating poor QoL. On comparison of the mean scores across the three age groups it was found that the QoL was better for the 4-7 years age group followed by 10.1-12 age group and the 7.1-10 year age. Although females had greater mean scores than males, a significant difference could not be obtained between the gender indicating QoL to be equivalent in both the groups. On comparison of the scores between no associated, one associated and more than one associated problems it was seen that the mean total scores for those who had no associated problems were higher when compared to those who had one or more than one associated problems which indicated better QoL in those children with no associated problems. However there was no significant difference found between the three groups. The QoL was higher for those who had attended intervention for a duration of more than one year when compared to those who had attended lesser than one year indicating that greater the duration of intervention, better was the QoL. However there was no significant difference obtained between the two groups.

It can be concluded from the study that the QoL was affected in all children with CP irrespective of severity, type, topographic distribution, age or gender. Hence it is essential to assess the QoL and also incorporate this goal of preserving or improving QoL during the intervention for these children. Moreover QoL should also be incorporated into the assessment protocol of these children.

Clinical implications of the study

- The CPQOL Questionnaire provides us with information on the parent perspective of the quality of life in the child.
- It would help in quantifying various difficulties in children in different domains by providing a quantitative score.

- These quantitative scores obtained from the parents will strengthen the clinical findings made by the speech-language pathologists and other relevant professionals regarding the various problems present in the child.
- This would help the speech-language pathologists in prioritizing the goals taken up during therapy and to monitor the progress achieved during intervention.

Future Directions

The study may be extended to multicentric large sample from different states of India. Different types of cerebral palsy can be taken into consideration. Parent proxy and self-reported studies may be carried out to find the extent of agreement or disagreement between them.

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ಭಾಗ-1

ನಿಮ್ಮ ಮಗುವಿನ ಭಾವನೆಗಳ ಬಗ್ಗೆ ನಿಮಗಿರುವ ಅಭಿಪ್ರಾಯಗಳು

1 - ಬಹಳ ದುಃಖಕರ-ವಾಗಿದೆ/ ದುಃಖದಿಂದ

2 - ದುಃಖಕರ-ವಾಗಿದೆ

3 - ದುಃಖವಾಗಿಯೂ ಇಲ್ಲ/ ಸಂತೋಷ-ವಾಗಿಯೂ ಇಲ

4 - ಸಂತೋಷ-ವಾಗಿದೆ/ ಸಂತೋಷದಿಂದ

5 - ತುಂಬಾ ಸಂತೋಷ-ವಾಗಿದೆ

(1) ಕುಟುಂಬ ಮತ್ತು ಸ್ನೇಹಿತರು

1. ನಿಮ್ಮಮಗುವು ಎಲ್ಲಾ ವಯಸ್ಸಿನ ಜನಗಳ ಜೊತೆ ಬೆರೆಯುವ ರೀತಿ/ವಿಧಾನ

1 2 3 4 5

2. ನಿಮ್ಮ ಮಗುವು ನಿಮ್ಮೊಟ್ಟಿಗೆ ಬೆರೆಯುವ ರೀತಿ

1 2 3 4 5

3. ತನ್ನ ಅಣ್ಣ, ತಂಗಿ ಮತ್ತು ಇತರೆ ಸಂಬಂಧಿಕರೊಡನೆ (ಮಕ್ಕಳ) ಜೊತೆ ಬೆರೆಯುವ ರೀತಿ/ವಿಧಾನ ಅಥವಾ ☐

ನನ್ನ ಮಗುವಿಗೆ ಯಾವ ಅಣ್ಣ, ತಮ್ಮ, ತಂಗಿ ಮತ್ತು ಇತರೆ ಚಿಕ್ಕಪ್ಪ ದೊಡ್ಡಪ್ಪನ ಮಕ್ಕಳು ಇಲ್ಲ

1 2 3 4 5

4. ಪ್ರೀಸ್ಕೂಲ್/ಬೇರೆ ಶಾಲೆಯ ಮಕ್ಕಳ ಜೊತೆ ಬೆರೆಯುವ ರೀತಿ (ನಿಮ್ಮ ಮಗುವು ಹೆಚ್ಚು ಶಾಲೆಗಳಿಗೆ ಹೋಗುತ್ತಿದ್ದರೆ ಯಾವ ಶಾಲೆಯಲ್ಲಿ ಹೆಚ್ಚಿನ ಸಮಯ ಕಳೆಯುವರು ಎಂಬುದನ್ನು ಯೋಚಿಸಿ)

1 2 3 4 5

5. ಪ್ರೀಸ್ಕೂಲ್/ಶಾಲೆಯ ಮಕ್ಕಳಲ್ಲದ ಬೇರೆ/ ಇತರೆ ಮಕ್ಕಳೊಡನೆ ಬೆರೆಯುವ ವಿಧಾನ/ ರೀತಿ

1 2 3 4 5

6. ಹಿರಿಯರ ಜೊತೆ ಬೆರೆಯುವ ರೀತಿ

1 2 3 4 5

7. ಶಿಕ್ಷಕರು ಅಥವಾ ಪೋಷಕರು/ಪೋಷಣೆ ಮಾಡುವವರ ಜೊತೆ ಬೆರೆಯುವ ರೀತಿ

1 2 3 4 5

8. ಸ್ನೇಹಿತರ ಜೊತೆ ಆಡಲು ಇರುವ ಸಾಮರ್ಥ್ಯ

1 2 3 4 5

9. ಮನೆಯ ಜನಗಳ ಜೊತೆ ಸೇರಿ ಹೊರಗಡೆ ಪ್ರವಾಸಕ್ಕೆ ಹೋಗುವಾಗ

1 2 3 4 5

10. ಹೇಗೆ ನಿಮ್ಮ ಅತೀ ಹತ್ತಿರದ ಮತ್ತು ದೂರದ ಸಂಬಂಧಿಕರಿಂದ ನಿಮ್ಮ ಮಗುವು ಅಂಗೀಕರಿಸಲ್ಪಟ್ಟ/ಸ್ವೀಕರಿಸಲ್ಪಟ್ಟ ರೀತಿ

1 2 3 4 5

11. ಹೇಗೆ ನಿಮ್ಮ ಮಗುವು ಪ್ರೀ ಸ್ಕೂಲ್/ಶಾಲೆಯ ಮಕ್ಕಳಲ್ಲದ ಮಕ್ಕಳಿಂದ ಸ್ವೀಕರಿಸಲ್ಪಟ್ಟಿದ್ದಾನೆ? (ನಿಮ್ಮ ಮಗುವು ಹೆಚ್ಚು ಶಾಲೆಗಳಿಗೆ ಹೋಗುತ್ತಿದ್ದರೆ ಯಾವ ಶಾಲೆಯಲ್ಲಿ ಆತನು/ಅವಳು ಹೆಚ್ಚು ಸಮಯವನ್ನು ಕಳೆಯುವರು ಎಂಬುದನ್ನು ಯೋಚಿ☐ಥವಾ ನನ್ನ ಮಗುವು ಯಾವ ಶಾಲೆಗೂ/ಪ್ರೀ ಸ್ಕೂಲಿಗೂ ಹೋಗುವುದಿಲ್ಲ.

1 2 3 4 5

12. ಪ್ರೀ ಸ್ಕೂಲ/ಶಾಲೆಯ ಮಕ್ಕಳಲ್ಲದವರಿಂದ ನಿಮ್ಮ ಮಗುವು ಹೇಗೆ ಸ್ವೀಕರಿಸಲ್ಪಟ್ಟಿದ್ದಾನೆ?

1 2 3 4 5

13. ಹಿರಿಯರಿಂದ ನಿಮ್ಮ ಮಗುವು ಹೇಗೆ ಸ್ವೀಕರಿಸಲ್ಪಟ್ಟಿದ್ದಾನೆ?

1 2 3 4 5

14. ಸಮಾಜದ ಜನರಿಂದ ಅವರು ಸ್ವೀಕರಿಸಲ್ಪಟ್ಟಿರುವ ರೀತಿ

1 2 3 4 5

15. ಅವರಿಗೆ ಅನಿಸುವ ಕೆಲಸವನ್ನು ಅವರು ಮಾಡಿ ಮುಗಿಸುವ ರೀತಿ/ವಿಧಾನ

1 2 3 4 5

ಭಾಗ 2: ಭಾಗವಹಿಸುವಿಕೆ

16. ಪ್ರೀ ಸ್ಕೂಲ್/ಶಾಲೆಯಲ್ಲಿ ಭಾಗವಹಿಸುವ ಸಾಮರ್ಥ್ಯ (ನಿಮ್ಮ ಮಗುವು ಹೆಚ್ಚು ಶಾಲೆಗಳಿಗೆ ಹೋಗುತ್ತಿದ್ದರೆ ಯಾವ ಶಾಲೆಯಲ್ಲಿ ಹೆಚ್ಚು ಸಮಯವನ್ನು ಕಳೆಯುತ್ತಿದ್ದಾನೆ ಎಂಬುದನ್ನು ಯೋಚಿಸಿ) ☐ ನನ್ನ ಮಗುವು ಶಾಲೆ/ಪ್ರೀಸ್ಕೂಲಿಗೆ ಹೋಗುವುದಿಲ್ಲ.

1 2 3 4 5

17. ಮನರಂಜನಾ ಕಾರ್ಯಕ್ರಮದಲ್ಲಿ ಭಾಗವಹಿಸಲು ಅವರಿಗಿರುವ ಸಾಮರ್ಥ್ಯ. ಉದಾ: ನೃತ್ಯ, ನಾಟಕ, ಸಂಗೀತ, ಕಲಾ, ಕೌಶಲ್ಯ, ಯೋಗ ಇತ್ಯಾದಿಯಲ್ಲಿ ತೊಡಗಿಸುವಿಕೆ.

1 2 3 4 5

18. ಕ್ರೀಡಾ ಚಟುವಟಿಕೆಗಳಲ್ಲಿ ಭಾಗವಹಿಸಲು ಅವರಿಗಿರುವ ಸಾಮರ್ಥ್ಯ. (ಈ ಪ್ರಶ್ನೆಯು ನಿಮ್ಮ ಮಗುವು ಕ್ರೀಡಾ ಚಟುವಟಿಕೆಗಳ ಬಗ್ಗೆ ಭಾಗವಹಿಸಲು ಇರುವ ಅನಿಸಿಕೆ ಹೊರತು ಭಾಗವಹಿಸುವಿಕೆ ಇಲ್ಲ) ಉದಾ: ಬೇರೆ ವಿಧಾನಗಳ ಒಳಾಂಗಣ ಹಾಗೂ ಹೊರಾಂಗಣ ಕ್ರೀಡೆಗಳನ್ನು ಆಡುವ ಸಾಮರ್ಥ್ಯ.

1 2 3 4 5

19. ಪ್ರೀ ಸ್ಕೂಲ್/ಶಾಲೆಯಿಂದ ಆಚೆಗೆ ಆಗುವ ಸಾಮಾಜಿಕ ಚಟುವಟಿಕೆಗಳಲ್ಲಿ ಭಾಗವಹಿಸುವ ಸಾಮರ್ಥ್ಯ. ಉದಾ: ಹೆಚ್ಚು ಜನಗಳು ಒಟ್ಟಾಗಿ ಸೇರಿ ಯೋಜನೆ ಮಾಡಿ ನಡೆಸುವ ಕಾರ್ಯಕ್ರಮಗಳಲ್ಲಿ ಭಾಗವಹಿಸುವಿಕೆ. (ಮದುವೆ, ಹುಟ್ಟುಹಬ್ಬ, ಪಾರ್ಟಿಗಳು ಇತ್ಯಾದಿ)

1 2 3 4 5

20. ತಮ್ಮ ಸಮುದಾಯದಲ್ಲಿ ಭಾಗವಹಿಸಲು ಅವರಿಗಿರುವ ಸಾಮರ್ಥ್ಯ. ಉದಾ: ಹಬ್ಬಗಳು, ರೋಟರಿ ಕ್ಲಬ್‌ಗಳು, ಪ್ರವಾಸಗಳು ಇತ್ಯಾದಿ.

1 2 3 4 5

ಭಾಗ 3: ಸಂವಹನ (ಕಮ್ಯೂನಿಕೇಷನ್)

21. ಅವರಿಗೆ ಚೆನ್ನಾಗಿ ಗೊತ್ತಿರುವ ವ್ಯಕ್ತಿಗಳ ಜೊತೆ ವಿಚಾರ ವಿನಿಮಯ/ಸಂವಹನ ಮಾಡುವ ವಿಧಾನ (ಯಾವ ರೀತಿಯ ವಿನಿಮಯವಾದರೂ ಪರವಾಗಿಲ್ಲ)

1 2 3 4 5

22. ಅವರಿಗೆ ಚೆನ್ನಾಗಿ ಗೊತ್ತಿಲ್ಲದ ವ್ಯಕ್ತಿಗಳ ಜೊತೆ ಸಂವಹನ ಮಾಡುವ ರೀತಿ (ಯಾವ ರೀತಿಯ ವಿನಿಮಯ/ಸಂವಹನವಾದರೂ ಪರವಾಗಿಲ್ಲ)

1 2 3 4 5

23. ಇತರೆ ಜನರು ನಿಮ್ಮ ಮಗುವಿನೊಡನೆ ಸಂವಹನ ಮಾಡುವ ರೀತಿ.

1 2 3 4 5

ಭಾಗ 4: ಆರೋಗ್ಯ

ನಿಮ್ಮ ಮಗುವಿನ ಭಾವನೆ ನಿಮಗೆ ಹೇಗೆ ಅನಿಸುತ್ತದೆ

24. ಅವರ ದೈಹಿಕ ಆರೋಗ್ಯ

1 2 3 4 5

25. ಅವರ ಚಲನವಲನಗಳು

1 2 3 4 5

26. ಅವರು ಮಲಗುವಾಗ

1 2 3 4 5

27. ಅವರ ಹೊರನೋಟ

1 2 3 4 5

28. ಸರಿಸಮಾನವಾಗಿ ತಮ್ಮ ವಯಸ್ಸಿನ ಮಕ್ಕಳ ಜೊತೆ ಶಿಕ್ಷಣದ ವಿಚಾರದಲ್ಲಿ ಇರುವ ಸಾಮರ್ಥ್ಯ

1 2 3 4 5

29. ದೈಹಿಕವಾಗಿ ತಮ್ಮ ವಯಸ್ಸಿನ ಮಕ್ಕಳ ಜೊತೆ ಉಳಿಸಿಕೊಳ್ಳುವ ಸಾಮರ್ಥ್ಯ

1 2 3 4 5

30. ಅವರು ತಮ್ಮ ಕಾಲುಗಳನ್ನು ಉಪಯೋಗಿಸುವ ರೀತಿ

1 2 3 4 5

31. ಅವರು ತಮ್ಮ ಕೈಗಳನ್ನು ಉಪಯೋಗಿಸುವ ರೀತಿ

1 2 3 4 5

32. ಮುಂದೆ ಬರುವ ಮೂರು ಪ್ರಶ್ನೆಗಳು ನಿಮ್ಮ ಮಗುವು ಹೇಗೆ ತನ್ನ ದಿನನಿತ್ಯದ ಚಟುವಟಿಕೆಗಳನ್ನು ಮಾಡಿ ಪೂರೈಸುವನು ಎಂಬ ನಿಮ್ಮ ಮಗುವಿನ ಭಾವನೆಯನ್ನು ಕುರಿತೇ ಹೊರತು ನಿಮ್ಮ ಮಗುವು ಚಟುವಟಿಕೆಗಳನ್ನು ಹೇಗೆ ಪೂರೈಸುವನೇ ಎಂಬುದರ ಬಗ್ಗೆ ಅಲ್ಲ.

1 2 3 4 5

33. ಅವರೇ ಸ್ವಂತವಾಗಿ ಬಟ್ಟೆಯನ್ನು ಧರಿಸುವ ಸಾಮರ್ಥ್ಯ

1 2 3 4 5

34. ಯಾರ ಸಹಾಯವು ಇಲ್ಲದೇ ತಾವೇ ತಿನ್ನಲು/ ಕುಡಿಯಲು ಇರುವ ಸಾಮರ್ಥ್ಯ

1 2 3 4 5

35. ತಾವೇ ಸ್ವಂತವಾಗಿ ಶೌಚಾಲಯವನ್ನು ಉಪಯೋಗಿಸುವ ಸಾಮರ್ಥ್ಯ

1 2 3 4 5

ಭಾಗ 5: ವಿಶೇಷ ಸಾಧನಗಳು

ನಿಮ್ಮ ಮಗುವಿನ ಅನಿಸಿಕೆ ಬಗ್ಗೆ ನೀವು ತಿಳಿದಿರುವ ರೀತಿ

36. ಮನೆಯಲ್ಲಿರುವ ವಿಶೇಷ ಸಾಧನಗಳು (ಉದಾ: ವಿಶೇಷವಾಗಿ ಕೂರಲು ಮಾಡಿರುವ ಕುರ್ಚಿಗಳು, ನಿಲ್ಲಲು ಮಾಡಿರುವ ಫ್ರೇಮ್‌ಗಳು, ವೀಲ್‌ಕುರ್ಚಿಗಳು, ವಾಕರ್‌ಗಳು ಇತ್ಯಾದಿ ☐ ವಾ ನನ್ನ ಮಗುವಿನ ಬಳ ಯಾವ ವಿಶೇಷ ಸಾಧನವು ಇಲ್ಲ.

1 2 3 4 5

37. ಸಮುದಾಯದಲ್ಲಿ ಲಭ್ಯವಿರುವ ವಿಶೇಷ ಸಾಧನಗಳು (ರ್‍ಯಾಂಪ್‌ಗಳು, ಎಸ್ಕಿಲೇಟರ್‌ಗಳು, ವೀಲ್‌ಚೇರ್‌ಗಳ ಉಪಯೋಗ) ಅಥವಾ ☐ ಸಮುದಾಯದಲ್ಲಿ ಯಾವ ವಿಶೇಷ ಸಾಧನಗಳ ಅವಶ್ಯಕತೆ ಇಲ್ಲ.

1 2 3 4 5

38. ಶಾಲೆಯಲ್ಲಿರುವ ವಿಶೇಷ ಸಾಧನಗಳು (ಉದಾ: ವಿಶೇಷವಾಗಿ ಕೂರುವ ಕುರ್ಚಿಗಳು, ನಿಲ್ಲುವ ಫ್ರೇಮ್‌ಗಳು, ವೀಲ್‌ಚೇರ್‌ಗಳು, ವಾಕರ್‌ಗಳು ಇತ್ಯಾದಿ) ಅಥವಾ ☐ ನನ್ನ ಮಗುವಿಗೆ ಯಾವ ವಿಶೇಷ ಸಾಧನೆಗಳು ಶಾಲೆಯಲ್ಲಿ ಇಲ್ಲ.

1 2 3 4 5

ಭಾಗ 6: ನೋವು ಮತ್ತು ಚಿಂತೆ/ಆತಂಕ

ಮುಂದೆ ಬರುವ ಕೆಲವು ಪ್ರಶ್ನೆಗಳು ನಿಮ್ಮ ಯಾವ ಸಂಗತಿಗಳಿಗೆ ಚಿಂತೆ/ಆತಂಕ ಪಡುತ್ತಾನೆ ಅಥವಾ ಆತನಿಗೆ ನೋವು ಉಂಟಾಗುತ್ತದೆ ಎಂಬುದನ್ನು ಪರೀಕ್ಷಿಸುತ್ತದೆ

1 – ಯಾವಾಗಲೂ

2 – ಅನೇಕ ಸಲ/ ಪದೇ ಪದೇ

3 – ಕೆಲವೊಮ್ಮೆ

4 – ಯಾವಾಗ- ಲಾದರೂ ಕೆಲವೊಮ್ಮೆ

5 – ಯಾವಾಗಲೂ ಇಲ್ಲ

39. ನಿಮ್ಮ ಮಗುವು ಆಸ್ಪತ್ರೆ ಅಥವಾ ಕ್ಲಿನಿಕ್‌ಗಳಿಗೆ ಹೋದಾಗ ಚಿಂತೆಗೊಳಗಾಗುವನೇ?

1 2 3 4 5

40. ಅನಾರೋಗ್ಯದ ಕಾರಣದಿಂದಾಗಿ ಶಾಲೆ/ಕ್ಲಿನಿಕ್ ಹೋಗಲು ಅಸಾಧ್ಯವಾದಾಗ ಚಿಂತೆಯನ್ನು ವ್ಯಕ್ತಪಡಿಸುವರೇ?

1 2 3 4 5

41. ನಿಮ್ಮ ಮಗುವು ಬೇರೆ ವ್ಯಕ್ತಿಗಳಿಂದ ನಡೆಸಿಕೊಳ್ಳುವುದರ/ ನೋಡಿಕೊಳ್ಳುವುದರ ಬಗ್ಗೆ ಆತಂಕ/ಚಿಂತೆಯನ್ನು ವ್ಯಕ್ತಪಡಿಸುವುದೇ?

1 2 3 4 5

42. ಮುಂದೆ ನಿಮ್ಮ ಮಗುವುದ ಯಾರು ಅವರ ಬಗ್ಗೆ ಕಾಳಜಿ ವಹಿಸಿ ನೋಡಿಕೊಳ್ಳುತ್ತಾರೆ ಎಂಬುದರ ಬಗ್ಗೆ ಚಿಂತೆ ಮಾಡುವುದಾ?

1 2 3 4 5

43. ನಿಮ್ಮ ಮಗುವು ಈ ತೊಂದರೆಯ ಬಗ್ಗೆ ಆತಂಕ ಪಡುವನೇ (ಸೆರಬ್ರಲ್ ಪಾಲ್ಸಿ)

1 2 3 4 5

44. ನಿಮ್ಮ ಮಗುವು ನೋವಾಗುವುದು ಎಂದು ನಿಮ್ಮ ಬಳಿ ಹೇಳುವನೇ?

1 2 3 4 5

45. ನಿಮ್ಮ ಮಗುವಿಗೆ ಎಷ್ಟರಮಟ್ಟಿಗೆ ನೋವು ಇದೆ?

1 – ಸಹಿಸಲಾರದ ನೋವು
2 – ತುಂಬಾ ನೋವು
3 – ಸ್ವಲ್ಪ ನೋವು
4 – ಬಹಳ ಸ್ವಲ್ಪ ನೋವು
5 – ನೋವೇ ಇಲ

46. ನಿಮ್ಮ ಮಗುವಿಗಿರುವ ನೋವಿನಮಟ್ಟದ ಬಗ್ಗೆ ಆವರಿಸಿರುವ ಅನಿಸಿಕೆ ಏನು?

1 – ಬಹಳ ಗಲಿಬಿಲಿ/ ಆತಂಕ ಮತ್ತು ದುಃಖ
2 – ದುಃಖ ಮತ್ತು ಆತಂಕ
3 – ದುಃಖ-ವಾಗಿಯೂ ಇಲ್ಲ/ ಸಂತೋಷ-ವಾಗಿಯೂ ಇಲ್ಲ
4 – ಸ್ವಲ್ಪಮಟ್ಟಿಗೆ ಆತಂಕ/ ಗಲಿಬಿಲಿ ಗೊಳ್ಳುವಿಕೆ
5 – ಗಲಿಬಿಲಿ/ ಆತಂಕಕ್ಕೆ ಒಳಗಾಗು-ವುದಿಲ್ಲ

47. ಮ್ಮ ಮಗುವುದ ಗಲಿಬಿಲಿ/ ಅನಾರಾಮದಾಯಕನಾಗುವುದೇ?

1 – ಯಾವಾಗಲೂ
2 – ಅನೇಕ ಸಲ/ ಪದೇ ಪದೇ
3 – ಕೆಲವೊಮ್ಮೆ
4 – ಯಾವಾಗ- ಲಾದರೂ ಕೆಲವೊಮ್ಮೆ
5 – ಯಾವಾಗಲೂ ಇಲ

48. ಎಷ್ಟರ ಮಟ್ಟಿಗೆ ನಿಮ್ಮ ಮಗುವು ಅನಾರಾಮ ದಾಯಕವಾಗುವುದು?

1 – ಬಹಳ ಮಟ್ಟಿಗೆ ಅನಾರಾಮ
2 – ತುಂಬಾ ಆನಾರಾಮ
3 – ಸ್ವಲ್ಪ ಅನಾರಾಮ
4 – ತುಂಬಾಕಡಿಮೆ ಅನಾರಾಮ
5 – ಅನಾರಾಮ ಅಲ್ಲ

49. ಅನಾರಾಮದ/ಗಲಿಬಿಲಿಗೊಳಗಾಗುವ ಪ್ರಮಾಣದ ಬಗ್ಗೆ ನಿಮ್ಮ ಮಗುವಿನ ಅನಿಸಿಕೆ ಹೇಗೆ?

1 – ಬಹಳ ಆತಂಕ ಮತ್ತು ದುಃಖ
2 – ದುಃಖ ಮತ್ತು ಆತಂಕ
3 – ದುಃಖ ವಾಗಿಯೂ ಇಲ್ಲ/ ಸಂತೋಷ-ವಾಗಿಯೂ ಇಲ್ಲ
4 – ಸ್ವಲ್ಪ ಮಟ್ಟಿಗೆ ಆತಂಕ/ ಗಲಿಬಿಲಿ ಗೊಳ್ಳುವಿಕೆ
5 – ಗಲಿಬಿಲಿ/ ಆತಂಕಕ್ಕೆ ಒಳಗಾಗುವುದಿಲ್ಲ

50. ನಿಮ್ಮ ಮಗುವುದ ಎಷ್ಟರ ಮಟ್ಟಿಗೆ ಖುಷಿಯಾಗಿದ್ದಾನೆ?

1 – ತುಂಬಾ ದುಃಖವಾಗಿ
2 – ದುಃಖ
3 – ದುಃಖ ವಾಗಿಯೂ ಇಲ್ಲ/ ಸಂತೋಷ-ವಾಗಿಯೂ ಇಲ್ಲ
4 – ಸಂತೋಷವಾಗಿ
5 – ತುಂಬಾ ಸಂತೋಷವಾಗ್ಗಿ

ಸೆಕ್ಷನ್ (2): ನಿಮ್ಮ ಅಭಿಪ್ರಾಯ/ಅನಿಸಿಕೆಗಳ ಬಗ್ಗೆ

ಭಾಗ 7: ಸೇವೆಗಳ ಉಪಯೋಗ

ಕೆಳಗಿನ ಪ್ರಶ್ನೆಗಳು ನಿಮಗಿರುವ ಅಭಿಪ್ರಾಯಗಳು ಹಾಗೂ ನಿಮ್ಮ ಮಗುವು ಎಷ್ಟರ ಮಟ್ಟಿಗೆ ಸೇವೆಗಳ ಉಪಯೋಗಗಳನ್ನು ಪಡೆಯುತ್ತಿದ್ದಾನೆ ಎನ್ನುವುದರ ಬಗ್ಗೆ

1 – ತುಂಬಾ ದುಃಖವಾಗಿ
2 – ದುಃಖ
3 – ದುಃಖ ವಾಗಿಯೂ ಇಲ್ಲ/ ಸಂತೋಷ-ವಾಗಿಯೂ ಇಲ್ಲ
4 – ಸಂತೋಷವಾಗಿ
5 – ತುಂಬಾ ಸಂತೋಷವಾಗಿ

51. ನಿಮ್ಮ ಮಗುವಿನ ಅಭಿಪ್ರಾಯಗಳು/ ಭಾವನೆಗಳು/ ಅನಿಸಿಕೆಗಳನ್ನು ಎಷ್ಟರಮಟ್ಟಿಗೆ ನೀವು ಆತ್ಮವಿಶ್ವಾಸದಿಂದ/ ಭರವಸೆಯಿಂದ ಹೇಳಬಲ್ಲಿರಿ.

1 2 3 4 5

52. ನಿಮ್ಮ ಮಗುವಿಗೆ ದೊರಕುವ ಚಿಕಿತ್ಸೆಗಳ ಉಪಯೋಗ/ ಸಮೀಪಿಸುವಿಕೆ

1 2 3 4 5

53. ನಿಮ್ಮ ಮಗುವಿಗೆ ತರಬೇತಿ/ತೆರಪಿಗಳಿಗೆ ಸುಲಭವಾಗಿ ಸಮೀಪಿಸಲು ಸಾಧ್ಯವಾಗುತ್ತಿದೆಯೇ? (ಉದಾ: ಫಿಸಿಯೋತೆರಪಿ, ಮಾತಿನ ತೆರಪಿ, ಆಕ್ಯುಪೇಷನ್ ತೆರಪಿ)

1 2 3 4 5

54. ವಿಶೇಷವಾದ ಮೆಡಿಕಲ್ ಅಥವಾ ಶಸ್ತ್ರಚಿಕಿತ್ಸೆಗಳಿಗೆ ನಿಮ್ಮಮಗುವು ಉಪಯೋಗ ಹೊಂದಿದ್ದಾನೆಯೇ?

1 2 3 4 5

55. ಪೀಡೀಯಾಟ್ರಿಷನ್/ಮಕ್ಕಳ ವೈದ್ಯರಿಂದ ನಿಮ್ಮ ಮಗುವಿಗೆ ಸಲಹೆಗಳನ್ನು ಕೇಳುವುದರಲ್ಲಿ ನಿಮ್ಮ ಸಾಮರ್ಥ್ಯ

1 2 3 4 5

56. ನಿಮ್ಮ ಮಗುವಿಗೆ ಸಿಗುತ್ತಿರುವ ಸಮುದಾಯದ ಸೇವೆಗಳು ಹಾಗೂ ಅನುಕೂಲಗಳ ಉಪಯೋಗ (ಉದಾ: ಕಿಂಡರ್‌ಗಾರ್ಡನ್, ಶಾಲೆ, ಚೈಲ್ಡ್‌ಕೇರ್, ಶಾಲೆಯ ನಂತರ ಇರುವ ಕಾರ್ಯಕ್ರಮಗಳು ಹಾಗೂ ಸಮ್ಮರ್ ಕ್ಯಾಂಪ್‌ಗಳು)

1 2 3 4 5

ನಿಮ್ಮ ಬಗ್ಗೆ

1 – ತುಂಬಾ ದುಃಖವಾಗಿ

2 – ದುಃಖ

3 – ದುಃಖ ವಾಗಿಯೂ ಇಲ್ಲ/ ಸಂತೋಷ–ವಾಗಿಯೂ ಇಲ್ಲ

4 – ಸಂತೋಷವಾಗಿ

5 – ತುಂಬಾ ಸಂತೋಷವಾಗಿ

57. ನಿಮ್ಮ ದೈಹಿಕ ಆರೋಗ್ಯ?

1 2 3 4 5

58. ನಿಮ್ಮ ಕೆಲಸದ ಜಾಗದಲ್ಲಿ ಅಥವಾ ☐ ನಾನು ಕೆಲಸವನ್ನು ಮಾಡುತ್ತಿಲ್ಲ

1 2 3 4 5

59. ನಿಮ್ಮ ಕುಟುಂಬದ ಆರ್ಥಿಕ ಪರಿಸ್ಥಿತಿ?

1 2 3 4 5

60. ನೀವು ಎಷ್ಟರಮಟ್ಟಿಗೆ ಖುಷಿಯಾಗಿದ್ದೀರಾ?

1 2 3 4 5

61. ನಿಮ್ಮ ಮಗುವನ್ನು ನೋಡಿಕೊಳ್ಳಲು ನಿಮಗಿರುವ ಲಭ್ಯತೆಯ ಸಮಯ?

1 2 3 4 5

കൂട്ടുകാര്,കുടുംബം,ആരോഗ്യം,സ്കൂള് എന്നി ജീവിതമേഖലകളെപ്പറ്റി നിങ്ങളുടെ കുട്ടിക്ക് എന്ത് അനുഭവപ്പെട്ടിട്ടുണ്ടാവും എന്ന് അറിയുവാന് ഞങ്ങള് ചില ചോദ്യങ്ങള് ചോദിക്കുന്നതാണ്. ഓരോ ചോദ്യവും "നിങ്ങളുടെ കുട്ടിക്ക് എന്ത് അനുഭവപ്പെടുന്നുണ്ടാവാം?" എന്ന് തുടങ്ങുന്നു. നിങ്ങളുടെ കുട്ടിക്ക് എന്ത് അനുഭവപ്പെടുന്നുണ്ടാവാം എന്നതാണ് നിങ്ങള് രേഖപ്പെടുത്തേണ്ടത്. ചില സന്ദര്ഭങ്ങളില് നിങ്ങളുടെ കുട്ടിക്ക് എന്താണ് അനുഭവപ്പെടുന്നത് എന്ന് മനസ്സിലാക്കാന് ബുദ്ധിമുട്ടാണ്. ദയവായി നിങ്ങളുടെ കഴിവിന് ഒത്തവണ്ണം ഉത്തരം നല്കാന് ശ്രമിക്കുക. നിങ്ങളുടെ കുട്ടിയുടെ അനുഭവത്തെ പ്രതിനിധീകരിക്കുന്ന ഏറ്റവും ഉചിതമായ അക്കത്തിന് ചുറ്റും ഒരു വട്ടം വരക്കുക. 0 (തീരെ സന്തോഷമില്ല) മുതല് 4 (വളരെയധികം സന്തോഷം) വരെയുള്ള ഏത് അക്കത്തിന് ചുറ്റും നിങ്ങള്ക്ക് വരയ്ക്കാവുന്നതാണ്.

ഈ ചോദ്യാവലി നിങ്ങളുടെ കുട്ടിക്ക് എന്ത് അനുഭവപ്പെടുന്നു/ തോന്നുന്നു എന്ന് അറിയുന്നതിനുവേണ്ടിയാണ്,മറിച്ച് എന്ത് ചെയ്യാന് കഴിയും എന്ന് അറിയുന്നതിനുവേണ്ടിയല്ല.

വിഭാഗം 1: കുട്ടിയുടെ വികാരങ്ങളെ വിലയിരുത്തുക

1. കുടുംബവും കൂട്ടുകാരും

നിങ്ങളുടെ കുട്ടിക്ക് എന്ത് അനുഭവപ്പെടുന്നുണ്ടാവാം...

0 **തീരെ സന്തോഷമില്ല**

1 **സന്തോഷമില്ല**

2 **സന്തോഷവുമില്ലദു:ഖവുമില്ല**

3 **സന്തോഷമുണ്ട്**

4 **വളരെയധികംസന്തോഷമുണ്ട്**

1) എല്ലാപ്രായത്തിലുമുള്ളകുട്ടികളുമായിഒത്തുപോകുന്നതിനെപ്പറ്റി

0 1 2 3 4

2) നിങ്ങളുമായിഒത്തുപോകുന്നതിനെപ്പറ്റി

0 1 2 3 4

3) സഹോദരങ്ങളുമായിഒത്തുപോകുന്നതിനെപ്പറ്റി

0 1 2 3 4

അഥവാ☐കുട്ടിക്ക്സഹോദരങ്ങള് ഇല്ല

4)സ്കൂള് അല്ലെങ്കില് പ്രീസ്കൂളിലെകുട്ടികളുമായിഒത്തുപോകുന്നതിനെപ്പറ്റി (നിങ്ങളുടെകുട്ടിഒന്നിലധികംസ്കൂളുകളില് പോകുന്നുണ്ടെങ്കില് ഏറ്റവുംഅധികംസമയംചിലവിടുന്നസ്കൂളിനെപ്പറ്റിചിന്തിക്കുക)

0 1 2 3 4

☐

അഥവാ എന്റെകുട്ടിസ്കൂള്/ പ്രീസ്കൂളില് പോകുന്നില്ല

5) പ്രീസ്കൂളിന്പുറത്തുള്ളകുട്ടികളുമായിഒത്തുപോകുന്നതിനെപ്പറ്റി

0 1 2 3 4

6) മുതിര്ന്നവരുമായിഒത്തുപോകുന്നതിനെപ്പറ്റി

0 1 2 3 4

7) അദ്ധ്യാപകര്/ അവരെശുശ്രൂഷിക്കുന്നവരുമായിഒത്തുപോകുന്നതിനെപ്പറ്റി

0 1 2 3 4

8) കൂട്ടുകാരുമായികളിക്കുവാനുള്ളകഴിവിനെപ്പറ്റി

0 1 2 3 4

9) കുടുംബത്തോടൊപ്പംയാത്രകള് പോകുന്നതിനെപ്പറ്റി

0 1 2 3 4

10) അടുത്തുംഅകന്നതുമായബന്ധുക്കള് തന്നെഎങ്ങനെഅംഗീകരിക്കുന്നുഎന്നതിനെപ്പറ്റി

0 1 2 3 4

11) പ്രീസ്കൂള് അഥവാസ്കൂളിലെകുട്ടികള് തന്നെഎങ്ങനെഅംഗീകരിക്കുന്നുഎന്നതിനെപ്പറ്റി (നിങ്ങളുടെകുട്ടിഒന്നിലധികംസ്കൂളുകളില് പോകുന്നുണ്ടെങ്കില് ഏറ്റവുംഅധികംസമയംചിലവിടുന്നസ്കൂളിനെപ്പറ്റിചിന്തിക്കുക)

0 1 2 3 4

അഥവാ☐ന്റകുട്ടിസ്കൂള് അല്ലെങ്കില് പ്രീസ്കൂളില് പോകുന്നില്ല

12) പ്രീസ്കൂള് അഥവാസ്കൂളിന്പുറമെയുള്ളകുട്ടികളാല് എങ്ങനെഅംഗീകരിക്കപ്പെടുന്നുഎന്നതിനെപ്പറ്റി

0 1 2 3 4

13) മുതിര്ന്നവരാല് എങ്ങനെഅംഗീകരിക്കപ്പെടുന്നുഎന്നതിനെപ്പറ്റി

0 1 2 3 4

14) സമൂഹത്തിലുള്ളആളുകള് തന്നെഎങ്ങനെഅംഗീകരിക്കുന്നുഎന്നതിനെപ്പറ്റി

0 1 2 3 4

15) ആവശ്യമുള്ളകാര്യങ്ങള് ചെയ്യാന് കഴിയുന്നതിനെപ്പറ്റി

0 1 2 3 4

2. പങ്കാളിത്തം

നിങ്ങളുടെകുട്ടിക്ക്എങ്ങനെഅനുഭവപ്പെടുന്നുണ്ടാവാം

- - - - - 0 **തീരെസന്തോഷമില്ല**

1 **സന്തോഷമില്ല**

2 **സന്തോഷവുമില്ലദുഃഖവുമില്ല**

3 **സന്തോഷമുണ്ട്**

4 **വളരെയധികംസന്തോഷമുണ്ട്**

16) പ്രീസ്കൂള്/ സ്കൂളില് പങ്കെടുക്കാന് കഴിയുന്നതിനെപ്പറ്റി

(ഒന്നിലധികംസ്കൂള്/ പ്രീസ്കൂളില് പോകുന്നുണ്ടെങ്കില് ഏറ്റവുംഅധികംസമയംചിലവിടുന്നസ്കൂളിനെപ്പറ്റിചിന്തിക്കുക)

0 1 2 3 4

അഥവാഎ☐കുട്ടിസ്കൂള്/ പ്രീസ്കൂളില് പോകുന്നില്ല

17) വിനോദങ്ങളില് പങ്കെടുക്കുന്നതിനുള്ളകഴിവിനെപ്പറ്റി

ഉദാ: ഡാന്സ്,നാടകം,പാട്ട്,കല,യോഗതുടങ്ങിയവ

0 1 2 3 4

18) കായികവിനോദങ്ങളില് പങ്കെടുക്കുന്നതിനുള്ളകഴിവിനെപ്പറ്റി

(പങ്കെടുക്കാന് കഴിയുമോഎന്നതിലുപരിപങ്കെടുക്കാനുള്ളസ്വന്തംകഴിവിനെപ്പറ്റികുട്ടിക്ക്എന്തുതോന്നുന്നു എന്ന്അറിയാന്വേണ്ടിയാണ്)

0 1 2 3 4

19) സ്കൂള്/ പ്രീസ്കൂളിന്പുറമെയുള്ളചടങ്ങുകളില് പങ്കെടുക്കാനുള്ളകഴിവിനെപ്പറ്റി

(വളരെയധികംജനങ്ങള് പങ്കെടുക്കുന്നചടങ്ങുകള് -ജന്മദിനം,പാര്ട്ടികള് തുടങ്ങിയവ)

0 1 2 3 4

20) സമൂഹത്തില് പങ്കെടുക്കാനുള്ളകഴിവിനെപ്പറ്റി

ഉദാ: ഉത്സവങ്ങള്,വിനോദയാത്രകള്

0 1 2 3 4

3. ആശയവിനിമയം

നിങ്ങളുടെകുട്ടിക്ക്എങ്ങനെഅനുഭവപ്പെടുന്നുണ്ടാവാം

0 **തീരെസന്തോഷമില്ല**

1 **സന്തോഷമില്ല**

2 **സന്തോഷവുമില്ലദു:ഖവുമില്ല**

3 **സന്തോഷമുണ്ട്**

4 **വളരെയധികംസന്തോഷമുണ്ട്**

21) വളരെയധികംഅടുത്തുപരിചയമുള്ളവരുമായിആശയവിനിമയംനടത്തുന്നരീതിയെപ്പറ്റി

(എന്ത്ആശയവിനിമയമാര്ഗംഉപയോഗിക്കും)

0 1 2 3 4

22) അധികംപരിചയമില്ലാത്തആളുകളുമായിആശയവിനിമയംനടത്തുന്നരീതിയെപ്പറ്റി

0 1 2 3 4

23) മറ്റുള്ളവര് തന്നോട്ആശയവിനിമയംനടത്തുന്നരീതിയെപ്പറ്റി

0 1 2 3 4

- - - - -

4. ആരോഗ്യം

നിങ്ങളുടെകുട്ടിക്ക്എങ്ങനെഅനുഭവപ്പെടുന്നുണ്ടാവാം

24) അവരുടെശാരീരികആരോഗ്യത്തെപ്പറ്റി

0 1 2 3 4

25) ഒരിടത്തുനിന്നുമറ്റൊരിടത്തേക്ക്നടന്നുനീങ്ങാനുള്ളകഴിവിനെപ്പറ്റി

0 1 2 3 4

26) അവര് എങ്ങനെഉറങ്ങുന്നുഎന്നതിനെപ്പറ്റി

0 1 2 3 4

27) അവരുടെബാഹ്യമായരൂപത്തെപ്പറ്റി

0 1 2 3 4

28) പഠനകാര്യങ്ങളില് സമപ്രായക്കാരായകുട്ടികളെപ്പോലെപഠിക്കുവാനുള്ളഅവരുടെകഴിവിനെപ്പറ്റി

0 1 2 3 4

29) ശാരീരികമായകാര്യങ്ങളില് സമപ്രായക്കാരായകുട്ടികളെപ്പോലെആയിരിക്കാന് കഴിയുന്നതിനെപ്പറ്റി

0 1 2 3 4

ശാരീരികഅവയവങ്ങള് ഉപയോഗിക്കുന്നതിനെപ്പറ്റിനിങ്ങളുടെകുട്ടിക്ക്എന്ത്തോന്നുന്നുഎന്ന്അറിയാനുള്ളതാണ്അടുത്തരണ്ട്ചോദ്യങ്ങള്;മറിച്ച്'കഴിയുമോഇല്ലയോ'എന്ന്അറിയാനല്ല

30) കാലുകള് ഉപയോഗിക്കുന്നരീതിയെപ്പറ്റി

0 1 2 3 4

31) കൈകള് ഉപയോഗിക്കുന്നരീതിയെപ്പറ്റി

0 1 2 3 4

ദൈനംദിനകര്ത്തവ്യങ്ങള് നിര്വ്വഹിക്കുന്നതിനുള്ളകഴിവിനെപ്പറ്റികുട്ടിക്ക്എന്ത്തോന്നുന്നുഎന്ന്അറിയുന്നതിനുവേണ്ടിയാണ്അടുത്തമൂന്നുചോദ്യങ്ങള്;മറിച്ച്കര്ത്തവ്യങ്ങള് നിര്വ്വഹിക്കുവാന് 'കഴിയുമോഇല്ലയോ'എന്നറിയാന് വേണ്ടിയല്ല.

32) സ്വയംവസ്ത്രംധരിക്കുവാന് ഉള്ളകഴിവിനെപ്പറ്റി

0 1 2 3 4

33) സ്വന്തമായികഴിക്കുവാനോകുടിക്കുവാനോഉള്ളകഴിവിനെപ്പറ്റി

0 1 2 3 4

34) സ്വന്തമായിശൌചാലയം (ടോയിലേറ്റ്) ഉപയോഗിക്കുവാനുള്ളകഴിവിനെപ്പറ്റി

0 1 2 3 4

5. പ്രത്യേകഉപകരണങ്ങള്

നിങ്ങളുടെകുട്ടിക്ക്എന്ത്അനുഭവപ്പെടുന്നുണ്ടാവാം

35) കുട്ടിയുടെസഹായത്തിനായിവീട്ടില് ഉപയോഗിക്കുന്നപ്രത്യേകഉപകരണങ്ങളെപ്പറ്റി

ഉദാ: പ്രത്യേകമായിതയ്യാറാക്കിയിരിക്കുന്നഇരിപ്പിടം,വീല്ചെയറുകള്,വാക്കറുകള് തുടങ്ങിയവ)

0 1 2 3 4

അഥവാ ☐ രീതിയിലുള്ളഉപകരണങ്ങള് ഉപയോഗിക്കുന്നില്ല

36) സ്കൂളില് ലഭ്യമാകുന്നപ്രത്യേകഉപകരണങ്ങളെപ്പറ്റി

ഉദാ: പ്രത്യേകമായിതയ്യാറാക്കപ്പെട്ടഇരിപ്പിടം,വീല്ചെയറുകള്,വാക്കറുകള് തുടങ്ങിയവ.

0 1 2 3 4

37) സമൂഹത്തില് ലഭ്യമാകുന്നപ്രത്യേകഉപകരണങ്ങളെപ്പറ്റി

ഉദാ: പ്രത്യേകമായനടപ്പാത,വീല്ചെയര്,എസ്കലേറ്റര് മുതലായവ

0 1 2 3 4

അഥവാ☐ന്റകുട്ടിക്ക്പ്രത്യേകമായിനിര്മ്മിച്ചഉപകരണങ്ങള് ആവശ്യമില്ല

6. വേദനയുംആവലാതികളും

അടുത്തകുറച്ചുചോദ്യങ്ങള് നിങ്ങളുടെകുട്ടിയെഅസ്വസ്ഥതപ്പെടുത്തുന്നകാര്യങ്ങള് എന്തെല്ലാമായിരിക്കാംഎന്നവിലയിരുത്തുന്നതിനുവേണ്ടിയുള്ളതാണ്

0 **എപ്പോഴും**

1 **ഇടയ്ക്കിടയ്ക്ക്**

2 **വല്ലപ്പോഴും**

3 **വളരെവിരളമായി**

4 **ഒരിക്കലുമില്ല**

38) ഹോസ്പിറ്റല്/ ക്ലിനിക്ക്സന്ദര്ശനങ്ങള് കുട്ടിയെഅസ്വസ്ഥതപ്പെടുത്തുന്നുണ്ടോ?

0 1 2 3 4

39) ആരോഗ്യപ്രശ്നങ്ങള് കാരണംസ്കൂള്/ ക്ലിനിക്കില് പോകാന് സാധിക്കാത്തതിനെപ്പറ്റിആവലാതിയുണ്ടോ

0 1 2 3 4

40) മറ്റുള്ളആളുകള് കുട്ടിയെപരിപാലിക്കുന്നതില് കുട്ടിക്ക്അസ്വസ്ഥതയുണ്ടോ?

0 1 2 3 4

41) ഭാവിയില് തന്നെആര്പരിപാലിക്കുംഎന്നതിനെപ്പറ്റികുട്ടിക്ക്ആവലാതിയുണ്ടോ?

0 1 2 3 4

42) ഈഅവസ്ഥ (സെറിബ്രല് പാൾസി) ഉള്ളതിനെപ്പറ്റികുട്ടിക്ക്വിഷമംഅഥവാആകുലതഉണ്ടോ?

0 1 2 3 4

43) വേദനയെപ്പറ്റികുട്ടിപരാതിപ്പെടാറുണ്ടോ?

0 1 2 3 4

44) എത്രയധികംവേദനകുട്ടിഅനുഭവിക്കുന്നുണ്ട്?

0 അത്യധികം വേദന - 1 വളരെയധികം വേദന 2- കുറച്ച് വേദന

- 3 വളരെ കുറച്ച് വേദന - - 4 തീരെ വേദന ഇല്ല

45) താന് അനുഭവിക്കുന്നവേദനയെപ്പറ്റികുട്ടിക്ക്എന്ത്തോന്നുന്നു?

0 വളരെയധികം വിഷമവും സങ്കടവും ഉണ്ട് 1 വിഷമവും സങ്കടവും ഉണ്ട്

- - 2 സന്തോഷവുമില്ല സങ്കടവുമില്ല 3 ചെറുതായി വിഷമം ഉണ്ട്

- - 4 തീരെ വിഷമം ഇല്ല

46) കുട്ടിക്ക്അസ്വസ്ഥതഅനുഭവപ്പെടാറുണ്ടോ?

0 എപ്പോഴും 1- ഇടയ്ക്കിടയ്ക്ക് 2- വല്ലപ്പോഴും

-- -- - 3- വളരെ വിരളമായി 4. ഒരിക്കലുമില്ല

47) കുട്ടിക്ക്എത്രയധികംഅസ്വസ്ഥതഅനുഭവപ്പെടുന്നു?

0 അത്യധികംഅസ്വസ്ഥത ഉണ്ട് 1 വളരെയധികംഅസ്വസ്ഥത ഉണ്ട്

2 കുറച്ച്അസ്വസ്ഥതഉണ്ട് 3 വളരെകുറച്ച്അസ്വസ്ഥതഉണ്ട്

4 തീരെഅസ്വസ്ഥതഇല്ല

48) അനുഭവിക്കുന്നഅസ്വസ്ഥതയെപ്പറ്റികുട്ടിയുടെതോന്നല്

-- -- - 0 അത്യധികംവിഷമവുംസങ്കടവുംഉണ്ട്, 1 വളരെയധികംവിഷമംഉണ്ട്,

2 കുറച്ചുവിഷമവുംസങ്കടവുംഉണ്ട്, 3 വളരെക്കുറച്ചുവിഷമവുംസങ്കടവുംഉണ്ട്,

4 ഒട്ടുംവിഷമംഇല്ല

49) നിങ്ങളുടെകുട്ടിഎത്രയധികംസന്തുഷ്ടനാണ്

- - -- 0 വളരെയധികംദുഃഖമുണ്ട് 1 ദുഃഖിതനാണ്

2 സന്തോഷവുമില്ലദുഃഖവുമില്ല, 3 സന്തോഷംഉണ്ട്

4 വളരെയധികംസന്തോഷംഉണ്ട്

വിഭാഗം 2: നിങ്ങളുടെവികാരങ്ങള് അറിയുന്നതിന്

7. സേവനങ്ങളുടെലഭ്യത

അടുത്തകുറച്ച്ചോദ്യങ്ങള്
നിങ്ങളെപ്പറ്റിയുംനിങ്ങളുടെകുട്ടിക്ക്ലഭിക്കുന്നസേവനങ്ങളെപ്പറ്റിയുംനിങ്ങൾക്ക്എന്ത്തോന്നുന്നു എന്നതിനെവിലയിരുത്തുന്നു

1)നിങ്ങളുടെകുട്ടിക്ക്എന്ത്തോന്നുന്നുഎന്ന്ശരിയായിപരാമർശിക്കാന് കഴിയുന്നതില് നിങ്ങൾക്ക്എത്രത്തോളംആത്മവിശ്വാസമുണ്ട്?

0 തീരെആത്മവിശ്വാസമില്ല
1 വളരെകുറച്ച്ആത്മവിശ്വാസമുണ്ട്
2 കുറച്ച്ആത്മവിശ്വാസമുണ്ട്
3 വളരെയധികംആത്മവിശ്വാസമുണ്ട്
4 അത്യധികംആത്മവിശ്വാസമുണ്ട്

നിങ്ങൾക്ക് എന്ത്തോന്നുന്നു?

0 വളരെയധികംസങ്കടമുണ്ട്
1 സങ്കടമുണ്ട്
2 സന്തോഷവുമില്ലസങ്കടവുമില്ല
3 സന്തോഷമുണ്ട്
4 വളരെയധികംസന്തോഷമുണ്ട്

2). നിങ്ങളുടെകുട്ടിക്ക്വേണ്ടചികിത്സകളുടെലഭ്യതയെപ്പറ്റി?

0 1 2 3 4

3) നിങ്ങളുടെകുട്ടിക്കുള്ളതെറാപ്പിയുടെലഭ്യതയെപ്പറ്റി

ഉദാ: ഫിസിയോതെറാപ്പി,സ്പീച്ച്തെറാപ്പി,ഒക്യുപെഷണല് തെറാപ്പിമുതലായവ.

0 1 2 3 4

4) മെഡിക്കല് അഥവാശസ്ത്രക്രിയസംബന്ധമായശുശ്രൂഷകളുടെലഭ്യതയെപ്പറ്റി

0 1 2 3 4

5) ഒരുശിശുരോഗവിദഗ്ധനില്നിന്ന്ഉപദേശങ്ങള് നേടുവാനുള്ളനിങ്ങളുടെകഴിവിനെപ്പറ്റി

0 1 2 3 4

6) സാമൂഹികസൌകര്യങ്ങളുടെയുംസംവിധാനങ്ങളുടെയുംലഭ്യതയെപ്പറ്റി?

ഉദാ: അങ്കന്വാടി,സ്കൂള്,ശിശുശുശ്രൂഷാകേന്ദ്രംമുതലായവ

0 1 2 3 4

7) പ്രീസ്കൂള് അഥവാസ്കൂളില് നിങ്ങളുടെകുട്ടിയുടെപഠനത്തിനായിഅധികമായിലഭിക്കുന്നസഹായങ്ങളെക്കുറിച്ച്?

0 1 2 3 4

നിങ്ങളെക്കുറിച്ച്.........

0 വളരെയധികംസങ്കടമുണ്ട്

1 സങ്കടമുണ്ട്

2 സന്തോഷവുമില്ലസങ്കടവുമില്ല

3 സന്തോഷമുണ്ട്

4 വളരെയധികംസന്തോഷമുണ്ട്

8) നിങ്ങളുടെശാരീരികആരോഗ്യം

0 1 2 3 4

9) നിങ്ങളുടെജോലിയെപ്പറ്റി

0 1 2 3 4

അഥവാണ ☐ ജോലിചെയ്യുന്നില്ല

10) നിങ്ങളുടെകുടുംബത്തിന്റെസാമ്പത്തികസ്ഥിതിയെപ്പറ്റി

0 1. 2 3 4

11) നിങ്ങള് എത്രത്തോളംസന്തുഷ്ടനാണ്

0 1 2 3 4

12) നിങ്ങളുടെകുട്ടിയെശുശ്രൂഷിക്കാന് കിട്ടുന്നസമയത്തെപ്പറ്റി

0 1 2 3 4