

# **Pain in non-verbal children with severe multiple disabilities**

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A qualitative study of parents perceptions about pain  
in their non-verbal child with severe multiple  
disabilities and how pain affects activities of daily  
living in the family.

Karen Kleivene

Master student

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## **Abstract**

**Title:** Pain in non-verbal children with severe multiple disabilities. A qualitative study of parents perceptions about pain in their non-verbal child with severe multiple disabilities, and how it affects activities of daily living in the family.

**Purpose:** The purpose of this master thesis is to describe parents' experiences with pain in children with severe multiple disabilities, and how they perceive that pain affects naturally occurring activities of daily living in the family. This knowledge can help more effective healthcare provision for pain that better meets the needs of the family.

**Research questions:** This project explored the following two research questions: How do parents perceive and communicate about pain and discomfort in a non-verbal child with severe multiple disabilities? How does pain and discomfort in a non-verbal child with severe multiple disabilities affect activities of daily living in the family?

**Theoretical Framework:** This project views a child with severe multiple disabilities within the context of his or her family, and in mutual relation to other systems as presented in Bronfenbrenner's Ecological Developmental Model (1979). The first research question is based on perspectives on interaction and symbolic interactionism. The second research question includes perspectives on interaction, coping and caregiving.

**Method:** This project is a qualitative study involving parents of school-aged children with severe multiple disabilities experiencing pain or discomfort. Data collection occurred through semi-structured life world interview technique. The data were analyzed by a phenomenological approach, utilizing a thematic analysis inspired by Giorgi (1975) as described by (Malterud, 2008).

**Findings:** Pain in a child with severe multiple disabilities appears to have a negative effect on naturally occurring activities of daily living in the family. Parents have expert practical knowledge regarding their child and identifying and handling pain behaviors and appearances within the context of naturally occurring activities of daily living in the family.

**Keywords:** Pain, non-verbal child, severe multiple disability, interaction, ADL

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## **1.0 Introduction and actual literature**

Through many years of experience working as a physical therapist with children, I have seen pain behaviors develop over time in children with severe multiple disabilities, especially in pre-teenage and teenage years. These children often communicate through behaviors, body language and non-verbal cues which caregivers and professionals need to interpret. I acknowledge that pain behaviors may not be truly representative of the child's subjective experience of their pain, and this is disturbing to me along with experiencing that pain behaviors can be difficult to observe and interpret and pain can often be difficult to localize. Pain appears to interfere with functional activities such as: care giving, transfers and participation in daily school activities, and appears to affect a child's mood, humor and interactions with caregivers and professionals at school. It appears to take many years before children receive medical treatment for their pain, and I often wonder why this seems to be the case. This has led me to a desire to acquire more knowledge about how parents perceive pain in their child with severe multiple disabilities and how a child's pain may influence normally occurring activities of daily living in the context of the family.

### **1.1 Published research findings on pain in disabled children**

Pain in children appears to have received increased attention in the literature the past decade. This section will present a short summary of the findings in the literature which are deemed relevant for this project including topics such as pain, pain's influence on activities of daily living, pain assessment and management. Results of studies will give background information on the subject of pain in disabled children and the effects on ADL. Gaps in the knowledge base will be noted which will give rise to this project's research questions.

#### **1.1.1 Definition of pain**

Pain is seen as a subjective and complex multidimensional phenomenon (Schechter et al., 2003) encompassing physical and psychological elements. The International Association for the Study of Pain (IASP) (2001) describes pain as “*an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such*

*damage*” (in Roscigno, 2002:123). As this definition implies, both the pain sensation and pain perception are involved. Deyo et al., (2004) state that pain serves as a protective function by warning an individual about a potential or ongoing problem and is accompanied by expressive behaviors that can be noticed by others (Craig, 2004).

Pain can be acute or chronic. Acute pain arises from a short episode of tissue injury or inflammation, is referred to as nociceptive, and lasts a short period of time (Schechter et al., 2003). Acute pain can arise from illness, trauma, medical procedures, etc. Nociceptive pain can have a somatic or visceral origin, and is often described as: aching, sharp, stinging or throbbing (Roscigno, 2002). The IASP defines chronic pain as any pain that exceeds three months duration (Schechter et al., 2003), and is often referred to as neuropathic pain. Perquin et al., (2000) include recurrent pain for more than three months in their definition of chronic pain. Chronic neuropathic pain can develop from damage to the central or peripheral nervous system, and is often described as: stabbing, shooting or burning (Roscigno, 2002, Schechter et al., 2003). Yet, diagnostic efforts may not identify tissue damage or pathophysiological processes in many who suffer from pain (Craig, 2009).

## **1.2 Incidence and sources of pain in disabled children**

Children with developmental disabilities suffer from the same sources of pain that occur in the general child population such as: acute pain from bumps, scrapes, headaches, ear aches and typical childhood diseases (Schechter et al., 2003). In addition, children with significant neurological impairments appear to be at a greater risk for pain due to factors such as: medical problems and procedures, behavioral idiosyncrasies and difficulties in interpreting their pain behaviors (McGrath et al., 1998). Children with Cerebral Palsy (CP) may experience pain from a variety of factors such as: orthopedic and neurologic problems, gastrointestinal problems, surgery and medical procedures, and rehabilitative interventions (McKearnan et al., 2004). Activities of daily living (ADL), eating and swallowing, and spasticity are also reported as possible sources of pain in children with significant neurological impairment (Oberlander et al., 1999b). In a study of 101 children with severe cognitive impairment, 37 were reported having chronic pain from gastrointestinal problems, musculoskeletal conditions, infections (Breau et al., 2003b).

Pain is now seen as a frequent secondary problem in children with CP (Roscigno, 2002, Ehde et al., 2003, Chalkiadis, 2001). Children with a more severe degree of CP or cognitive impairment appear to have a higher pain frequency than those with a milder impairment (Houlihan et al., 2004, Berrin et al., 2007, Liptak et al., 2001, Breau et al., 2003a). In a sample of 198 children with moderate to severe CP, pain was found to be related to the severity of the motor impairment and the presence of a gastrostomy (Houlihan et al., 2004). The severity of motor impairment in children with CP is reported to be associated with an increased incidence of hip dislocation, contracture, deformity and scoliosis (Donnelly et al., 2008), conditions which have been reported to cause pain (McKearnan et al., 2004, Chalkiadis, 2001).

Studies claim that daily pain is common in children with significant neurological and cognitive impairment (Oberlander and O'Donnell, 2001, Breau et al., 2003a, Hunt et al., 2004). Seventy-one percent of 50 healthcare professionals reported perceiving daily pain in children with significant neurological impairment (Oberlander & O'Donnell, 2001). Forty-two percent of the 140 children with severe neurological and cognitive impairments age 1-18 years in Hunt et al., (2004) were reported by their parents as having troublesome pain either all of the time or on a daily basis, and 20% were reported as having daily severe or very severe pain. In a study of 94 caregivers of children and adolescents age 3-18 years with moderate to profound cognitive impairment, pain was experienced on 18% of the days surveyed and by 35-52% of the children each week (Breau et al., 2003a). Yet, one located study shows that 86% of 405 Canadian children with CP and Gross Motor Functional Classification Scale (GMFCS) level I – V did not have pain, and the researchers did not find evidence supporting the relationship between the degree of motor impairment and pain (Kennes et al., 2002). As of note, 40% of their population had GMFCS level IV-V; children with severe impairment. These researchers comment that their findings are generalizable to other children in the study area and possibly to other populations with similar health assessment and management systems.

Research appears to focus on the incidence of physical pains in this population, as few studies were located regarding psychological pains in children with significant neurological or cognitive impairment. Psychological pains can be described as “*an internal response to noxious psychological stimuli*”, and may vary in subtype and degree of intensity (Mee et al., 2006:681). Williams et al., (2003) suggested that chronic physical and psychological pain can lead to depression, and that depression can increase the perception of chronic physical pain in



(Mee et al., 2006). In a multicenter population based study of 818 children aged 8-12 years with all types of CP, over 40% were at high risk for poor mental health and children with pain or greater cognitive impairment were at highest risk (Parkes et al., 2008). In a further study focusing on 279 children with hemiplegic CP from this same study population, over 25% of the children appeared to present with significant psychological problems which is twice as much as the general population (Parkes et al., 2009). These researchers support routine screening for psychological problems in this population due to their high prevalence, their impact on the child and the family, and the potential for treatment (Parkes et al., 2009).

### **1.3 Impact of pain on a disabled child and the family**

It is necessary for healthcare professionals to understand how pain affects a child with disabilities and their family, to be able to provide services that better meet their needs and have the potential of improving their health and quality of life. This section will present the findings in the literature related to pains affect on ADL and sleep.

#### **1.3.1 Pains influence on ADL and participation**

Daily pain appears to affect activities of daily living (ADL) and participation in usual activities. Oberlander & O'Donnell, (2001) investigated pain-related beliefs of 50 professionals with multidisciplinary background working with children and adolescents with significant neurological impairment. Eighty-four percent of the professionals reported pain to interfere with routine ADL including: bed lying, sitting, transfers, feeding and oral care. In Houlihan et al., (2004) pain appeared to be correlated with missed days from school, days spent in bed and less participation in children's usual activities. In a qualitative study of 13 parents of children with CP and severe multiple disabilities living in Sweden, parents reported that pain reduced their child's well-being and prevented them from participating in their usual daily activities (Ståhle-Oberg & Fjellman-Wiklund, 2009).

Pain appears to have a negative effect on adaptive functioning, including areas of motor ability, communicative and social function, and daily living skills (Breau et al., 2007). This study included caregivers of 63 children age 3-18 years with varying degrees of cognitive

impairment. When in pain, children with profound cognitive impairment showed a 21-29% reduction in adaptive function, and children with severe cognitive impairment showed a 13% reduction in adaptive function. Thus, it appears that children with more severe cognitive impairment experience greater reductions in adaptive functioning when they experience pain. Greater reductions of function were noted across all domains with greater intensity of pain.

### **1.3.2 Pains influence on sleep**

Children with physical disabilities have a variety of medical conditions that can cause sleep disturbances such as: seizures, pain, abnormal muscle tone, respiratory and digestive problems, behavioral problems, incontinence, and difficulties with changing positions (Hemmingsson et al., 2009, Wright et al., 2006). Sleep problems appear common in children with physical impairment and cognitive impairment (Hemmingsson et al., 2009, Wright et al., 2006, Robinson and Richdale, 2004, Chalkiadis, 2001), and appear to occur in 48% -73% of the study populations. Sleeping problems were reported by 57.7% of the 149 parents of children with all degrees of cognitive impairment age 4-18 years, compared to 33.3% in typically developing children (Robinson & Richdale et al., 2004). Sleep problems were reported by 48% of 505 parents of children with physical disabilities aged 1-16 years, and 23% of these were perceived as serious (Hemmingsson et al., 2009). Thirty-seven percent of the children in this study were reported as needing nighttime attention every night. Wright et al., (2006) studied included 178 children with physical disabilities and 67 typical children, and found that children with physical disabilities woke up at night more frequently than typically developing children (66% versus 34,41%).

Pain appears to be the strongest contributing factor to sleep problems and need for nighttime attention in children with physical disabilities (Hemmingsson et al., 2009, Wright et al., 2006, Nolan et al., 2000, Chalkiadis, 2001). Lewin & Dahl (1999) suggest that pain sensations can negatively affect sleep onset and interfere with deep sleep and continuity of sleep. In Chalkiadis (2001) the source of pain was located to the hip or back in 55% of the 22 children with CP, and spasticity was reported as a possible source of pain since it can contribute to deformity, subluxation, dislocation, etc. Pain was reported as the most frequent cause for sleeping problems in 29% of the 178 children with physical disabilities (Wright et al., 2006). In Hemmingsson et al., (2009) problems relaxing, nightmares, pain and other medical

problems were the most common reported causes for sleep problems and pain (OR=7.6) was found to be related to the need for nighttime attention.

Lewin & Dahl, (1999) report that consequences of disturbed and insufficient sleep can include: tiredness, low motivation, emotional changes, changes in attention, performance, control of behavior, and increased perception of pain. Several studies report that sleep problems in children appear to be a major stress factor that can affect parents' daily lives and their health (Chu & Richdale, 2009, Hemmingsson et al., 2009, Robinson & Richdale, 2004, Wright et al., 2006). Seventy-four percent of the 505 parents in Hemmingsson et al. (2009) reported that their child's sleep difficulties affected their daily life in a moderate to severe degree, and over a third reported a negative effect on their own health. Poor maternal sleep quality was found significantly related to depression, anxiety and stress in 46 mothers of children age 2-12 years with developmental disorders (Chu and Richdale, 2009). Sixty-five percent of the parents of 178 children with disabilities reported that their child's sleep pattern affected their own sleep, and they slept less than parents of typically developing children (Wright et al, 2006). These caregivers also reported that insufficient sleep had a negative effect on the children's participation in social and academic activities, and that 11% of the 178 children with disabilities fell asleep unintentionally during the day.

Parents reported using medications, massage, changing positions and stretching to alleviate pain during sleep (Wright et al., 2006). When pain was addressed and treated in children with CP, most children began sleeping through the night (Chalkiadis, 2001). Several studies support interventions for pain and sleep problems in children, since this may have a positive effect on the well-being of children and their caregivers (Wiggs and Stores, 2001, Barlow et al., 2006, Wright et al., 2006). Yet, some studies report that parents may hesitate seeking advice for their child's sleep problems, due to assuming that it is a part of the underlying condition or that professionals seldom ask them about sleep problems (Chervin et al., 2001, Robinson and Richdale, 2004, Wright et al., 2006). Chevrin et al., (2001) recommend improved communication between professionals and caregivers about the prevalence of sleep problems and treatment possibilities. Robinson & Richdale, (2004) state that professionals will require information and training in assessment and management of sleep problems in children with cognitive impairment.

### **1.3.3 Summary**

Daily pain appears to affect daily activities, participation in usual activities and sleep quality in children with disabilities. Sleep difficulties and the need for nighttime attention appear to occur frequently in this population, and pain seems to be the strongest contributing factor. Sleep difficulties in a child also affect the parents sleep and may negatively affect their health and well-being. Studies seldom appear to specify which activities of daily living are affected negatively by pain. Knowledge of this can help healthcare professionals give advice and treatment for pain at an earlier point in time, thus possibly preventing unnecessary suffering.

### **1.4 Communicating pain**

An extended amount of research has focused on the role of facial expressions that occur during pain and its important role in social communication of pain (Deyo et al., 2004). Facial expressions and their behavioral consequences appear to be influenced by the context in which these expressions occur, and context plays an important role in appropriately deciphering their meaning (de Gelder et al., 2006). Hadjistavropoulos & Craig (2002) present a social communication model of pain describing the processes in which pain is expressed through behavioral displays and perceived by an observer. The perception of pain in another appears to be influenced by psychological, behavioral and contextual factors. Studies show that the context, characteristics of the sender, and the observers' sensitivity to the behavior and their beliefs and attitudes can influence pain interpretation and management (Hadjistavropoulos and Craig, 2002, Craig, 2004, Martel et al., 2008). Thus, it is necessary to understand pain in the social realities of those affected by pain including both the observer and the person in pain (Craig, 2009).

Interpreting pain behaviors in others relies on empathy, where personal experience with pain appears to increase the empathic reaction of the observer (Goubert et al., 2005). Sensitivity of the mother was found significantly associated with an infants' expression of acute pain during immunization, and stress regulation after 1 minute (Din et al., 2009). Intrusive caregiving appeared to increase infants' reactivity to pain and slowed regulation of pain distress after an acute painful procedure in this study. It is proposed that how one perceives pain in another and how one acts on that perception, can affect the others well-being (Craig, 2004).

### **1.4.1 Assessing pain in children with severe disabilities**

A number of studies report a risk for unrecognized and unmanaged pain in children with severe neurological impairment (Hadden and von Baeyer, 2002, Carter et al., 2002, Roscigno, 2002, Ståhle-Oberg and Fjellman-Wiklund, 2009). The underestimation and undertreatment of pain appears due to inadequate pain assessment in children, based on study results (Merkel and Malviya, 2000). Healthcare professionals in Oberlander & O'Donnell, (2001) report difficulties in assessing pain. Only 20% of the 50 healthcare professionals in this study perceived that pain was adequately expressed and/or located and 69% did not find typical assessment methods very helpful in identifying the presence or location of pain. These methods included: changes in vital signs and standard behavioral and facial assessment scales.

Pain appears difficult to assess and research in children with severe multiple disabilities due to communicative and cognitive impairments. These children often communicate through the use of sounds, body language and behaviors, and are reliant on caregivers who know them well and can interpret their cues (Ståhle-Oberg and Fjellman-Wiklund, 2009, Carter et al., 2002). Supportive and specialized relationships with caregivers is needed to enable these individuals to express their needs and desires and influence their environment (Vlaskamp and van der Putten, 2009). Thus, it appears that the role of parents who know their child well, may be critical in the assessment and treatment of pain (Hadden and von Baeyer, 2002). Yet, parents report that it can be very difficult to assess pain's intensity and differentiate pain from other feelings of discomfort (Nolan et al., 2000, Ståhle-Oberg and Fjellman-Wiklund, 2009), and it can take many years to learn to distinguish and interpret pain behaviors (Ståhle-Oberg and Fjellman-Wiklund, 2009). There are few studies that focus on how caregivers perceive pain in children with serious neurological difficulties and how their opinions affect pain management (Schechter et al., 2003).

It is proposed that assessment of pain can often be difficult, requires interpersonal sensitivity, standardized assessment measures with good psychometric properties, and attentive judgment (Hadjistavropoulos and Craig, 2002). Healthcare providers must often rely on proxy reports of caregivers who know the child well, since these children are unable to self-report their subjective experience of pain. However, researchers within this field do not agree as to the differences in estimation of pain between parents and professionals. Several studies suggest that parents are competent in providing objective ratings of their child's behavior during pain

(Breau et al., 2002, Hunt et al., 2004, Voepel-Lewis et al., 2005). Stallard et al., (2002b) propose that parents may underestimate pain in their children yet they also appear to be more accurate at identifying pain than healthcare professionals. However, when standardized measures were applied, Hunt et al., (2004) suggested that ‘knowing the child’ did not appear to affect test scoring between parent and professional.

#### **1.4.2 Factors that may affect expressions of pain in disabled children**

Several factors may affect the expression or interpretation of pain in children with cognitive impairment such as: idiosyncratic behaviors, motor impairments, and communicative impairments (Stallard et al., 2002b, Voepel-Lewis et al., 2005, Breau et al., 2000). Studies suggest less intense behavioral responses to minor painful stimulus in children with developmental delays, cognitive impairment and adolescents with CP, compared with the general population (Oberlander et al., 1999a, Gilbert-MacLeod et al., 2000). In a study of 24 children with developmental delay and 31 typically developing children age 2-6 years, it was observed that children with developmental delay presented with less or no distress response to a painful stimulus compared to typically developing children who were noted to cry/scream more to a painful stimulus (Gilbert-Macleod et al., 2000). In this study, children with developmental delay appeared less likely to seek social support when in pain compared with typically developing children (9.3% versus 22,8%), suggesting that children with developmental delay may have social-communication deficits.

Typical pain behaviors may not reflect pain in children with neurological impairment, and idiosyncratic behaviors may; which increases the risk for misinterpretation (Breau et al., 2000, McGrath et al., 1998). A withdrawn behavior and sleeping can be misinterpreted as no pain, yet a child may attempt to control pain by reducing activity and social interactions (Merkel & Malviya, 2000). A change in the child’s tone is a significant pain cue in Hunt et al., (2003). Some children may not have the physical ability to flinch or move the body part away from a painful stimulus. In McGrath et al., (1998) only 10 behavioral items were used by more than 50% of 22 primary caregivers of non-verbal children with cognitive impairment suggesting that these children may have individual responses to pain. Breau et al., (2000) noted that individuals with cognitive impairment may present with moaning and facial changes when they are not experiencing pain.

Reliable behavioral pain assessment may be difficult in individuals with chronic or recurrent pain since they may not present with typical pain behaviors or they may habituate or dissipate over time as an individual learns to adapt to pain (von Baeyer and Spagrud, 2007, Chambliss et al., 2002). Breau et al. (2003a) found that children with severe cognitive impairments who experienced more accidental pain episodes began showing fewer pain behaviors over time, proposing that children may adapt to accidental pains. Children who experienced more non-accidental episodes of pain appeared to show more pain behaviors, suggesting greater pain sensitivity in this study population. von Baeyer & Spagrud (2007:148) propose that symptoms that may indicate chronic pain in children are: *“increased irritability, low mood, difficulty with sleep, hostility, changes in appetite, and school performance”*.

Studies suggest that facial expressions may not be accurate in measuring pain in individuals with cognitive impairment, and this is disturbing due to the important role facial expressions have in communicating pain. Facial ‘freezing’ under an acute procedural pain was reported in approximately half the adults with severe to profound degrees of cognitive impairment, suggesting that assessment of facial expressions alone in this population may not be a reliable measure for the presence of pain (Defrin et al., 2006). A typical pain face was not observed during an acute noxious stimulus in 8 nonverbal adolescents with severe neurological impairments mean age 15 years, and they appeared to present with weak facial reactions to pain (Oberlander et al., 1999a). Yet, Stallard et al., (2002b) suggest, on the background of their study of 67 caregivers of communicatively impaired children, that only the behavior of “screwed up or distressed looking face” indicated pain correctly in 87% of the pain/non pain episodes on the Pediatric Indicator for Communicatively Impaired Children (PICIC).

### **1.4.3 Pain behaviors in children with severe disabilities**

Several researchers have developed behavioral assessment checklists for pain in children with severe neurological, cognitive and communicative disabilities (Breau et al., 2002, Hunt et al., 2004, McGrath et al., 1998, Stallard et al., 2002b). Yet, some individuals may vary in their ability to show some of the behaviors included on behavioral scales Hunt et al., (2004). These researchers state that there are no criterion-standard measures of pain in children with severe neurologic and cognitive impairments who are also unable to reliably communicate their pain experience. A short presentation of a few of the above mentioned studies will be presented.

McGrath et al., (1998) developed a checklist over the most frequent pain behaviors that primary caregivers observed in a study population of 20 individuals with cognitive impairment and communication difficulties. It is found to be valid for children from 3-18 years old with cognitive impairment and communication difficulties and has good reliability (McGrath et al., 1998). This checklist was later revised to the “Non-communicating Children’s Pain Checklist-Revised (NCCPC-R) and found to have excellent psychometric qualities, with a score of 7 or greater as indicative of pain, and presenting with 77% specificity and 84% sensitivity to pain (Breau et al., 2002). The researchers claim that pain behaviors in children with cognitive impairment can be observed and measured with the NCCPC-R, and that it can discriminate between if a child has pain or not. The NCCPC-R also appears to have validity and consistency when used in a natural setting such as the home environment. The checklist has seven categories: vocal, social, facial, eating/sleeping, activity, body/limb and physiological signs. Each category includes several behaviors such as: eats less, sleeps more/less, difficult behavior, withdrawal, grinding teeth, stiff, etc. More than 80% of caregivers reported cry and moaning as descriptive of pain (McGrath et al., 1998).

Breau et al, (2001) identified a core set of seven behavioral expressions that were predicative of pain: seeking comfort, gesturing to the part that hurts, tears, cranky, change in eyes, less active and gasping; with the strongest predictors of pain being seeking comfort, gesturing and tears. In another study, 90% of the 30 caregivers of children with communicative impairment and life threatening illness reported a set of six core behaviors depicting pain composing the PICIC: “*crying with or without tears; screaming, yelling, groaning or moaning; screwed up or distressed looking face; body appears stiff or tens; difficult to comfort or console; flinches or moves away if touched*” (Stallard et al., 2002a:146). This assessment checklist was found to correctly classify 87% of pain/non-pain episodes. A screwed up and distressed looking face had the strongest correlation with the presence and severity of pain. Presenting with more pain behaviors was significantly correlated with more severe pain in a follow-up prospective study of 67 caregivers (Stallard et al., 2002b).

## **1.5 Pain management in disabled children**

The IASP views adequate management of pain as a human right that health care providers have a duty to provide (Bond et al., 2006). Yet, it appears that effective and adequate pain



management is often difficult in disabled children. Studies present several factors that can impede or promote pain management in children, and some of these will be presented here.

### **1.5.1 Factors that may influence pain management**

Malviya et al., (2005) claimed that several factors hinder doctors and nurses from effective pain management in children with cognitive impairment, based on their study of 101 doctors and 114 nurses. These factors include the lack of valid pain assessment measures for children with cognitive impairments and insufficient education about pain assessment and management in this population. In a study of 162 nurses, medical diagnosis, parent and child characteristics, personal characteristics and work-related factors appear to affect nurses' decision-makings concerning children's non-pharmacological pain management in hospitals' (Pölkki et al., 2003). Personal factors in nurses, such as feelings of competency and insecurity, had the most affect. It is also suggested that the beliefs and attitudes of healthcare professionals can influence the recognition and management of pain (Oberlander 1999b). Hunt et al., (2003) propose that service organization can hinder pain assessment and management, based on the findings of their grounded study.

Parents' beliefs and attitudes may also influence the recognition and management of pain. Studies suggest that children with CP and their families may perceive that pain is a natural part of the underlying condition, and therefore may not seek medical help for pain (Russo et al., 2008, Ståhle-Oberg and Fjellman-Wiklund, 2009). Parents also report perceiving that their child tolerates pain well (Fanurik et al., 1999, Carter et al., 2002). Over half of the 145 parents of children age 4-20 with borderline to profound cognitive impairment reported that their child had decreased pain sensitivity and greater pain tolerance (Fanurik et al., 1999). Almost 2/3 of these parents perceived that their child with cognitive impairments experienced pain differently than did other children.

### **1.5.2 Pain interventions**

Surgical procedures and pharmacological treatments are used to treat spasticity related pain, yet Roscigno (2002) proposes that these treatment options may not be suitable for some

children and their families due to: possible side effects, the invasive nature, and the need for follow-up. Promising results in relieving pain were presented in a small study, where 85% of the 13 children with severe spastic quadriplegia CP who underwent bilateral reconstructive hip surgery were reported being pain free afterwards (Owers et al., 2001). Oberlander et al., (1999b) recommends that pain management should focus on the underlying sources of pain and by following The World Health Organization's analgesic ladder for everyday pain, opioids for acute/procedural pain and anti-spasticity medications for high tone.

Health professionals report that anti-inflammatory and anti-spasticity medications were most frequently used in pain management (Oberlander & O'Donnell, 2001). Yet, only 16% of 107 children with hemiplegic CP and pain reported using analgesia (Russo et al., 2008). Hunt et al., (2004) studied the effect of analgesic administration (paracetamol, codine, ibuprofen/diclofenac) on the behavior of 41 children with severe neurological and cognitive impairments who were unable to communicate, before and four hours post analgesic administration. 34 children were reported to have moderate to severe pain before analgesic administration. A reduction of pain test score of 50% or more was seen in 68% of the included children and 15% had less than 30% reduction. The majority of the children appeared to benefit from analgesic administration, yet some did not. The authors suggest that this may be due to insufficient dose or the treatment administered may not have been appropriate in relation to the type of pain experienced.

It is proposed that the use of pain medication alone is often not enough for effective pain relief, due to the complex and multidimensional nature of pain and it being more than just a sensory experience (Pölkki et al., 2003). These researchers state that fear and anxiety can cause more physical and emotional discomfort than the stressful stimulus itself. Due to this finding, they support the use of non-pharmacologic pain alleviation methods including: cognitive-behavioral and physical methods, providing emotional support and creating a comfortable environment. Parents report using a variety of techniques such as cuddling, comforting, distraction, entertaining in (Kankkunen et al., 2002), and massage, rest and sleep in (Russo et al., 2008). Health professionals reported that ice, hydrotherapy, splinting, and specialized seating equipment were useful pain modalities, and 64% of 50 reported that distraction and activity changes were useful (Oberlander & O'Donnell, 2002).

### **1.5.3 Joining knowledge bases**

Studies point out that parents perceive health professionals' management of their child's pain as lacking or inadequate, and that they have difficulties accessing adequate pain management for their child (Carter et al., 2002, Hadden and von Baeyer, 2002, Ståhle-Oberg and Fjellman-Wiklund, 2009). Many of the 43 parents of children with cognitive and physical disabilities age 1-19 years, reported difficulties in acquiring adequate pain management from healthcare services for their non-verbal children (Hadden & von Baeyer, 2002). Approximately 33% of the 145 parents in Fanurik et al., (1999) reported perceiving that pain in their child with cognitive impairment was treated differently than other children, due to difficulties assessing pain and underestimating and treating pain in this population.

It is claimed that if support is to be perceived as adequate by clients and their family, they must perceive that their views are listened to, respected and taken into account (Norman et al., 2003). Hunt et al., (2003) propose a model of pain assessment and management for children with severe to profound neurological impairment, based on the findings of their grounded theory study including parents of 21 non-verbal children. These researchers suggest that there are several important factors for adequate diagnostic and clinical and ethical decision making including: knowledge of the child, the population and the science. Knowing the child encompasses knowing them as a person and being able to recognize changes in their behavior in different contexts. Knowing the population involves having the capacity to notice similarities and differences between children, and recognizing patterns in behavior. Hunt et al., (2003) recommend inter-subjectivity between the professional, the caregivers and the child to explore what the pain experience means to them.

## **1.6 Chapter summary**

It appears as though a majority of studies support an increased incidence of pain in children with disabilities and that greater impairment is associated with a risk for greater pain. Yet, one located study did not confirm this finding (Kennes et al., 2002). Thus, there appears to be a need for further research regarding the incidence of pain in this child population. A number of studies report the risk of unnoticed and undertreated pain in children with disabilities (Breau et al., 2003a, Houlihan et al., 2004, Roscigno, 2002). Parents and healthcare professionals

have reported difficulties with assessing pain in children with significant neurologic and cognitive impairment, and this may be a compounding factor leading to the under-diagnosis and under-management of pain in this population. Parents have reported difficulties with deciphering pain from other feelings of discomfort and in evaluating pain intensity in children with communication difficulties (Ståhle-Oberg and Fjellman-Wiklund, 2009). Since children with severe multiple disability often rely on their caregivers to notice pain behaviors and help them regulate their pain distress, it is crucial to gain knowledge regarding caregivers role in assessment and management of pain. Yet, there are few studies that focus on how caregivers perceive pain in children with serious neurological difficulties and how their opinions affect pain management (Schechter et al., 2003).

## **1.7 The scope of this project**

### **1.7.1 Purpose of this project**

A number of researchers state that there are few studies that explore pain and the functional effects of pain on activities of daily living, participation and quality of life in children with developmental and physical disabilities (McKearnan et al., 2004, Engel et al., 2005, Ehde et al., 2003). Studies often focus on description, intensity and duration of pain, and there appears to be little knowledge regarding how caregivers perceive pain in children with serious neurological difficulties and how their opinions affect pain management (Schechter et al., 2003). The purpose of this master project is to describe how parents perceive pain in their non-verbal child with severe multiple disabilities and how pain affects naturally occurring activities of daily living in everyday family life. This knowledge can help more effective health care provision for pain that better meets the needs of the family.

This project is part of a Master program in Rehabilitation- with a Specialty in Children at Oslo University College, Norway. Bjørg Fallang, professor from the college, supervised this master project and functioned as mentor.

### **1.7.2 Research questions and their operationalization**

To obtain knowledge about how parents experience pain in their non-verbal child with severe disabilities, and how pain affects naturally occurring activities in every day family life, this project will explore the following research questions:

- How do parents perceive and communicate about pain and discomfort in their non-verbal child with severe multiple disabilities?
- How does pain and discomfort in a non-verbal child with severe multiple disabilities affect activities of daily living in the family?

#### Operationalization of the research question

##### **Severe multiple disabilities:**

Children with severe multiple disabilities have significant impairments in motor function, cognition and communication, and they require support in most every aspect of daily life (Petry et al., 2009a). The literature refers to these children as having: profound special needs, significant neurologic impairment, profound multiple disabilities and profound intellectual and multiple disabilities. Genetic abnormalities, degenerative diseases, metabolic imbalances, cerebral disorders and severe infections can all lead to profound multiple disabilities (de Geeter et al., 2002).

##### **Pain**

This project will focus on parents' perceptions of their child experiencing acute or chronic pain in naturally occurring activities of daily living in the family. This project will rely on Perquin et al., (2000) definition of chronic pain which is pain that reoccurs or occurs continuously for more than 3 months. The World Health Organization's International Classification of Impairments, Disabilities and Handicaps (ICF) (1980) suggests that pain in children can be experienced on four levels: disease or disorder, impairment, disability, and handicap (in Breau et al, 2007). This project's focus is on the disability which involves restriction of abilities and activities in the family.

## **Activities of daily living in everyday family life**

Parents have reported the following daily living situations as painful: assisted stretching, assisted walking, independent standing, toileting and putting on splint (Hadden and von Baeyer, 2002). Knowledge of pain affecting naturally occurring daily activities appears to be lacking in the literature, with only two studies located (Breau et al., 2007, Oberlander & O'Donnell, 2001). This current projects focus is on parents' perceptions of pain behaviors in naturally occurring ADL in the family such as: play, interaction, caregiving, dressing, toileting, feeding, sleep, mobility, social and leisure activities, etc.

## **2.0 Theoretical framework**

This section will present a description of this project theoretical framework. The child and family and their perceptions about their experience are viewed within Bronfenbrenner's Ecological model (1979). Perspectives on interaction will be discussed to understand how parents can perceive pain in their child. Research findings and perspectives on coping and caregiving will highlight pains affect on activities of daily living in the family context. Key findings in this project will be discussed in light of earlier studies on pain in children, and perspectives on family-centered care and power relations.

### **2.1 Bronfenbrenner's Ecological Developmental Model (1979)**

This project views a severely disabled child in the context of the family, and in mutual relation to other systems as presented in Bronfenbrenner's Ecological Developmental Model (1979). Bronfenbrenner points out the need to search for knowledge about how individuals experience and understand their situation from their social, cultural and historic context. The family system is involved in many other outside systems which mutually influence each other and are reliant on each other, and thus cannot be understood independent of each other (Gulbrandsen, 2006). Bronfenbrenner's Model includes 5 systems: micro-, meso-, exo-, macro- and time system, which I will present in short.

The microsystem encompasses the child's immediate family involving "*activities, social roles and interpersonal relationships* (Gulbrandsen, 2006:57). The mesosystem encompasses

connections with other environments an individual participates in, such as school, day care, respite, etc. The exosystem involves connections between two or more systems, where one has an indirect influence on the others such as parents' job, family social network, and society help and support programs. The macrosystem influences individuals reasoning and explanations in social negotiations of opinion, in mutual expectations and evaluations, and in 'taken for granted' ways of acting and doing. The time system involves development throughout a lifetime.

In regards to this project, a family's macrosystem will influence all the other systems since how parents define their role as parents, their child's role, their values, etc, will influence how they evaluate their situation and their expectations of their own and other systems. This project seeks knowledge of the parents' perspective of pain within the microsystem, acknowledging that their experiences with other systems mutually influence each other. Thus, parents' histories will be influenced by their relations and perceptions of their connections with other systems in their evaluation of their situation. Parent's stories are of retrospective experiences throughout their child's lifespan, allowing for insight into their changing experience over time. Distance to past pain experiences will include seeing past experiences in light of their perceptions of the present and thus may not be the same as when they experienced this period. Depending on where families are in their experience of their child's pain condition, whether they are currently experiencing a difficult period or if they inform about a past experience will have consequences for how they perceive these situations.

## **2.2 Theoretical perspectives on perceiving others feelings**

### **2.2.1 Perspectives on caregiver-child interaction**

To understand how parents perceive pain in their non-verbal child with severe multiple disabilities it is necessary to understand the role of relation and interaction in communicating and interpreting needs and wishes. Interaction between a severely disabled child and the parents occurs primarily on a non-verbal level through body language and sounds, where they mutually affect each other through contact and sharing of emotions. This project views this emotional interaction through Daniel Sterns model on infant development of the "sense of

self” as presented by Bjørg R. Hansen in (Gulbrandsen, 2006). Stern’s model includes four stages of development of the self, where each stage continues to organize experiences in different ways through life, and not just in the age periods they occur in development. Inter-subjective communication and affective attunement are key terms which are relevant for understanding how parents know what their child is feeling, and will be presented here.

Stern calls parents ‘self-regulating others’, since they help their child regulate, modulate and control their emotions and behaviors through interactions of calming them down or stimulating them. A child is reliant on interaction with a parent or significant other who is sensitive, emotionally involved, and who can interpret the child’s cues adequately. The child learns through experience that they can manipulate interaction, and participants mutually affect each other. This view is supported in Cramber-Berness (2007) who found that infants develop their experiences and expressions of pain over time through interactions with caregivers, and that caregivers actions have the potential to increase or decrease their infants pain-related distress in (Pillai Riddell and Racine, 2009). The development or utilization of additional pain behaviors, when pain proceeds over time, is also suggested in non-verbal children with cognitive impairment (Breau et al., 2000).

Inter-subjective communication is the ability to share affect states such as attention, intensions and feelings with another (Gulbrandsen, 2006, Stern, 1985). The caregiver tunes in to a child’s experience through affective intoning, and expresses that they are together with the child regarding the experience; they become synchronized. During affective intoning a caregivers actions express “*the quality of feeling of a shared affect state*” yet does not involve imitation of the infants’ behavioral expressions of their feelings (Stern, 1985:142). Caregivers communicate empathy through their bodily actions of rhythm, intensity, and length of expression. In this stage of development, the child uses emotions and cues from others to learn about the meanings of things to guidance for further action. Misinterpretations and misunderstandings of a child’s emotional experience or their behaviors may occur and Stern proposes that these can have clinical consequences later in life.

Relation and interaction are central factors in child development. In a dialectic relational perspective, humans mutually influence each other in a transactional process (Schibbye-Løvlie, 2002). One family member’s behavior does not only affect the other members, but it is also influenced by the other member’s response. Thus, humans need to be seen in their



context and in a mutual interaction to others, as also noted in Bronfenbrenner (1979). This project views the disabled child in relation to his or her parents and siblings, who mutually influence each other through their interactions. In light of perspectives on dialectic relation, the disabled child's feelings and emotions will have an effect on the other family members and the family members' responses to the child will influence the child's further actions in their interaction. This view appears to coincide with perspectives on symbolic interactionism, which I will present in the following section.

### **2.2.2 Symbolic Interactionism**

How can parents' know that their non-verbal child has pain or discomfort? Symbolic interactionism is one perspective that can help us understand this, and I regard it as an appropriate perspective to view this project's research questions. I will present a summary of the perspective from more recent years and how it pertains to this project's research questions. Symbolic interactionism is viewed as a theory and a perspective; a way to understand situations and a way to analyze social reality and social phenomena (Levin and Trost, 2005). As a perspective, it focuses on how people define their world through interactions with others, and how those definitions shape their actions. Levin & Trost (2005) present their interpretation of symbolic interactionism and point out five key features: defining the situation; interaction is social; we interact through the help of symbols; people are active; people act and behave in the present. These key features will be presented in general, and later as my interpretation pertaining to my research questions.

Humans label 'objects' they observe in their environment, including what a person is oriented towards and not only hard physical objects. Objects are given meanings and become symbols which humans use to interpret the environment and they become the reality they see (Charon and Cahill, 2001). The most usual symbols are words. When a word takes on the same or nearly the same meaning for both individuals involved in an interaction it becomes a symbol. Symbols must be significant for more than one individual, otherwise they are not symbols. Individuals may define the appearance of another, such as the way they are dressed or their body language and this may become a symbol. Defining an appearance or a behavior occurs mostly unconsciously and an individual acts in relation to their interpretation of the situation. Thomas & Thomas (1928) states that: *"If men define situations as real, they are real in their*

*consequences.*” (Charon & Cahill, 2001:136). This would imply that a person’s behavior needs to be observed in its context and how it exists for that person.

Social interactions involve role taking where a person “*imagines the world from the perspective of another*” (Charon & Cahill, 2001:109). Role taking involves inter-subjectivity where an individual empathizes with another to attempt to feel the way the other feels (Charon and Cahill, 2001, Røkenes and Hanssen, 2006). It requires prior experience with such feelings and involves closeness and boundary, meaning that one does not feel exactly the same as the other (Røkenes and Hanssen, 2006). Individuals attempt to understand another’s feelings and needs through their words and actions, and then act accordingly to their own definition of the situation.

Thomas (1928) points out that a person has knowledge from past experiences, that if they act in one way in a given situation then the other will most likely act in a certain way, in (Levin and Trost, 1996). Mead explains that humans actively perceive, define, and manipulate their environment to achieve goals (Charon and Cahill, 2001). Thus, individuals act in the present on the basis of knowledge from past experiences and a plan they have for the future. Mead explains that social interaction is a dynamic process that changes and develops with time (Levin & Trost, 2005:42). Individuals define situations, act accordingly, and adjust their actions as objects in the environment act back (Charon and Cahill, 2001). Thus, human interaction is never completely predictable, as definitions may change and affect previous interpretations and actions (Charon and Cahill, 2001).

Couch (1995) recommends observing an individuals’ behavior and actions to be able to understand the others attitudes, feelings or experiences (in Levin & Trost, 1996). In relation to this project, parents must strive to take on the role of their child to attempt to understand their child’s perspective. Since the children of focus in this project are non-verbal, parents must observe and define their child’s appearance and behaviors within their context. Behaviors become symbols of pain when their meaning becomes significant for both the child and his or her parents. Definitions arise from parents’ use of knowledge from past experiences in interpreting the new situation, and affect the actions parents take. The child in turn, will act back on the actions of the parent, and a continuous flow of actions occur in regards to the others actions. This occurs in a dynamic and changing fashion of defining behaviors, acting on definitions, and redefining definitions.

## **2.3 Theoretical perspectives related to how pain affects ADL in the family**

This project's second research question regarding how pain can affect ADL in everyday family life relies on relevant research findings on this subject and symbolic interactionism, which were described earlier. Perspectives on caregiving and coping will also be utilized, and will be described further. ADL occur in a social interaction between parents and their child involving parents defining and interpreting their child's behavioral expressions or appearances during these activities. Parents' definition of their child's behavior has consequences for their actions based on this definition. Parents and their child's actions to each other's actions will mutually influence each other in a dynamic process of defining, acting and redefining behaviors with the goal of completing ADL. The concept that family members mutually influence each other has been described earlier in Bronfenbrenner (1979) and a dialectic relational perspective.

### **2.3.1 Burden of caregiving of a child with special needs**

Recent studies focus on how the stresses of caregiving of children with disabilities can directly or indirectly affect parents' physical and psychological health (Barlow et al., 2006, Brehaut et al., 2004, Murphy et al., 2007, Singer, 2006). These studies point out several factors that may strongly influence caregiver psychological and physical health: child behavior, caregiver demands, and the perception of family function. A little over half of the 40 mothers of children with disabilities reported that the demands of caregiving negatively affected their physical and emotional health (Murphy et al, 2007). Caregivers of children with CP appear to experience greater distress, emotional and cognitive problems compared to the norm sample (Brehaut et al., 2004). They also report a larger degree of anxiety and depression compared to the norm, and anxious moods were found to be related to mother's perceptions of their child's sleeping difficulties (Barlow et al., 2006). Problems frequently reported by the 468 caregivers in Brehaut et al., (2004) included: physical problems such as back problems, migraine headaches, abdominal problems and other chronic physical problem.

Raina et al., (2005) suggest that child behavior, caregiving demands and family function can be the most important predictors of caregiver well-being based on the background their study of 468 primary caregivers of children with CP living in Canada. These authors recommend a family centered biopsychosocial framework approach including interventions and

preventative strategies to reduce the stress experienced by caregivers of children with CP. By supporting caregivers, they will then be better able to attend to their child's needs, and decrease the affect of their child's disability on them. Rosenbaum et al. (1998) indicated that families are better able to support and enhance their disabled child's well-being and development when they are healthy both physically and psychologically.

### **2.3.2 Coping**

Antonowsky (1974) defines coping as a successful adjustment to life situations (in Normann et al., 2000). Coping involves a perception of being in control of one's own situation and life. Lack of coping or feeling in control can lead to increased stress, strain and burden (Tetzchner et al., 2008). When parents define their child's behavior in a given situation to mean pain and discomfort, they will attempt to find out the cause of the pain and resolve it through their actions. If they can help their child feel better and resolve the problem they will experience competency and feelings of being in control of the situation. If parents struggle with finding out what is wrong with their child and how they can help them they may experience feelings of incompetency and not being in control of the situation. Both situations can affect how parents cope to the situation and their well-being. Parents coping strategies in these situations will influence how ADL is experienced for parents and child. Lerdal & Sørensen (2008) present that one of the goals in habilitation is to support families so they can cope with the re-adjustments and challenges they experience due to their disabled child (in Tetzchner et al., 2008).

## **2.4 Other relevant theoretical perspectives**

### **2.4.1 Family-centered service provision**

The World Health Organizations (ICF) framework highlights the environment as a key factor to health and well-being. Thus, healthcare professionals need to be aware of the relationship between a child's disability and the health and well-being of their caregivers. Several studies highlight the need for healthcare professionals to provide services that are family-centered and have the potential of enhancing the well-being of the family (Brehaut et al., 2004, Raina

et al., 2005). Parents perceptions and experiences with a family-centered professional support appears to be one of the strongest predictors of family well-being (Davis and Gavidia-Payne, 2009). Yet, studies also suggests that families caring for a child with disabilities have needs that are not being met by the health and social systems providing services to them (Fisher, 2001, Murphy et al., 2007). Few studies have investigated the needs of families with children with special health care needs and how they perceive that service should be implemented (Buran et al., 2009).

Dunst et al., (1991) defined family-centered care as “*a combination of beliefs and practices that define particular ways of working with families that are consumer driven and competency enhancing*” (in O’Neil and Palisano, 2000:173). Filer & Mahoney (1996) add that services meet the needs, concerns and goals identified by parents in (O’Neil and Palisano, 2000). Family-centered care is based on three basic premises: parents know their child best, families are unique and have individual needs, and a supportive family enables optimal child development and functioning (Rosenbaum et al., 1998). A key factor in family-centered approaches stresses the need for approaching the family as a whole, and involving families in decision making through healthcare professional and parent partnership (Davis & Gavidia-Payne, 2009). Family-centered care also focuses on improving family functioning, by giving parents information and skills to effectively interact with their disabled child, thus supporting their child’s development (Dempsey et al., 2009). Results of a literature review of 35 studies on family centered care concluded that there appears to be direct association between family-centered help giving and parent perceived locus of control, empowerment and self-efficacy (Dempsey and Keen, 2008). The perception that services are more family-centered strongly influences parent satisfaction with services (Law et al., 2003, Dempsey and Keen, 2008).

#### **2.4.2 Power relations**

Understanding power relations and their affect on others is important in all client-professional interaction, since it is always present no matter how aware individuals are of it (Oliver, 1996 in Normann et al., 2003:109, Skau 1999) Weber (1960) defined power as involving the possibility to implement one’s own will in a social relation (Skau, 1999). Using ones authority or power may either hurt or help the other, and having influence on another can be perceived as something positive if it can help in a positive way (Normann et al., 2003, Falardeau &

Durand, 2002). Ryburn (1996) proposes that a professionals' power may lie in their status, their personality and their knowledge and influences how they define problems, their decision makings, and to the degree in which they involve their clients in this process (Askeland and Molven, 2006).

Professionals and their clients have different knowledge bases. Professionals have scientific and theoretical knowledge and use a professional methodological perspective which tends to focus on cause and effect relations with a problem. Problems can easily be seen as due to the individual's diagnosis alone, detached from its context and the individual (Lorentzen, 2006). The client and their family have practical-relational knowledge and view situations through a "daily" perspective which Lorentzen (2006) perceives is the foundation for insight and wisdom. This view may imply that parents' knowledge should be viewed as expert knowledge, since they learn about their child's expressions and needs in the family context. Human activity is viewed as context dependent as there is a significant relation between knowledge development and context (Flyvbjerg, 1992). Experts' actions are described as "*intuitive, holistic and synchronized*" and they do not appear to utilize analytical considerations for their actions (Flyvbjerg, 1992:31). Their knowledge and experience appears internalized in their actions and may not be easily verbalized or intellectualized.

Skau (1999) informs that clients would like professionals to have a holistic understanding of their situation. To be able to obtain this, professionals will need to get to know their clients involving relational competency. Relational competency relies heavily on the communication process between partners, which needs to preserve the others interests. Røkenes & Hanssen (2006) propose an interactional communications perspective to help professionals learn to communicate in a purposeful fashion involving four perspectives: own perspective, the others perspective, the inter-subjective shared experience and the interaction perspective. The context in which a problem occurs is in focus since understanding the context helps individuals understand the meaning of what happens in a specific interaction. This model appears to coincide with the 3-jointed relation, involving two equal partners and the problem, as described by (Skjærveim, 2002).

The attitude an individual has to another is influenced by the perspective they use to evaluate situations (Lorentzen, 2006). Thus, knowledge and theory can construct the client and the professional and influence how a professional understands and acts in relation to a client

(Schibbye Løvlie, 2002). Enacting power over another can involve not taking the time to or not being interested in the others perspective, representing a lack of respect for the other (Falardeau and Durand, 2002, Norman et al., 2003). An individual must be capable of empathy to see another perspective and involves viewing the other as an equal partner and taking them seriously (Schibbye-Løvlie, 2002). Acknowledging a clients perspective and taking it seriously, represents a shift in power relation away from the more traditional relationship between a health professional and client (Normann et al., 2003). Interaction should occur through shared power, which St-Arnaud (1999) describes as mutual influence through respecting the others field of competence (in Falardeau & Durand, 2002). This shared power includes 3 types of competence: the clients, the professionals, and that which is shared between them. The latter is where decisions occur in a consensual manner, through a process of negotiation to find mutually acceptable solutions.

### **3.0 Method and Analysis**

#### **3.1 Design**

This project is a qualitative study involving parents of school-aged children with multiple disabilities experiencing pain/discomfort. Kvale (2009) points out that a phenomenological approach is recommended when a researcher is interested in learning about a social phenomenon from the viewpoint of those that experience it. This project wishes to highlight and describe the intricate qualities of pain as a phenomenon in children with multiple disabilities, as the parents experience it. Thus, a qualitative method is deemed appropriate with data collection occurring through interviews to obtain rich and descriptive data.

#### **3.2 Inclusion and exclusion criteria**

##### **3.2.1 Inclusion criteria**

Parents of school-aged children with severe multiple disabilities (physical, communicative and cognitive impairments) were included in this study. School-aged children were the target group due to the researchers experience with pain behaviors in these children. Children were

considered of school age as long as they were actively enrolled in a school program at the time of the interview. Severe multiple disabilities included diagnoses such as: chromosomal or other syndromes, static central nervous system disorders due to illness or CP with Gross Motor Function Classification Scale (GMFCS) levels IV-V. The GMFCS is a five level classification system which describes the gross motor functional ability of children and youths with CP (Palisano et al, 2007). Children at level IV have self-mobility limitations: roll or crawl on the floor, walk with physical assistance, need physical assistance with transfers and may use powered mobility. Children at level V have severe limitations in head and trunk control, need extensive support and physical assistance of adults for transfers, and are transported in a wheelchair. Children with other diagnosis were included into this study on the basis of similar functional limitations to children with CP at GMFCS level IV-V. In addition, children were not able to verbally communicate their experiences with pain.

It was desired that the child had presented with pain, either intermittent or continuous, over a period of at least six months prior to inclusion into this study. This time frame was chosen to give parents time to possibly seek medical attention and to experience pains influence on everyday family life. Pain or discomfort could occur in different body parts, and be experienced in a variety of daily family life situations f.eks: play, transfers, mobility, positioning, care giving, feeding, or sleep.

### **3.2.2 Exclusion criteria**

Children who presented with post-operative pain were not included in this project, since this condition is likely temporary. Parents of children the researcher had treated within the past 10 years were not accepted into this study, to lessen the chance of bias.

## **3.3 Participants**

### **3.3.1 Recruitment procedures**

Parents were recruited through 5 special schools in 2 neighboring counties in Norway, to help increase the anonymity of participants and to generate enough informants interested in



participating in this project. These schools sent a letter of information about this project (see appendix II), to parents of 41 children with severe multiple disabilities. The master student had no knowledge of those who received the letter. Families volunteered to participate in this project by signing an attached letter of informed consent which was then mailed to the master student. Participation was voluntary and the participants were informed that they could reserve themselves from the study at any time. Parents of seven school-aged children with severe multiple disabilities initially agreed to participate in this project. The master student contacted parents by telephone, for an initial screening to check if they matched the inclusion criteria. Five families were included in this project, and two families did not meet the inclusion criteria and were excluded. Parents received further information about the project, the demographic information form (see appendix) and the NCCPC-R checklist (see appendix) which were then mailed to them.

### 3.3.2 Demographics

This project included five children between the ages of 8-20 years old, including three boys and two girls. Two children had a diagnosis of static CNS disorder, two children had a genetic disorder and one child had a developmental disorder. All five children had epilepsy. None of the children had functional expressive language. Three children stood with support, and two could walk short distances with support yet they had poor balance. Four of the children had either younger or older siblings. Parents were between the ages of 35-54 years old and worked 60-100% or studied. Four of the seven parents interviewed had health professional/medical background.

**Table 1:** Characteristics of included children (n=5)

Characteristic	N	Characteristic	N
Sex		Impairments	
Boy	3	Cognitive	5
Girl	2	Communicative	5
Diagnosis		Motor	5
Static CNS disorder	2	Visual	2
Genetic Disorder	2	Hearing	1
Developmental disability	1	Upright Mobility	
Seizure disorder	5	Walks with support (short distance)	2
		Stands with support	3

### **3.4 Procedure**

A fieldwork diary was maintained throughout the project period. This encompassed valuable information about the research process and the master student's reflections over data obtained. Interviews were scheduled, and parents could choose if they would prefer to be interviewed together or separately. They could also choose an appropriate setting for the interview; for example at their home, work office or at the researcher's office. All interviews were done in the parents' homes, and two parent families chose to be interviewed together. Two interviews involved single mothers. Interviews were in Norwegian, lasted from 1-1 ½ hours and were audio-recorded.

#### **3.4.1 Written information**

Parents were asked to preview and score, if time allowed, the Norwegian version of the Non-Communicating Children's Pain Checklist (NCCPC-R) which is a pain profile for children age 3-18 years old (McGrath et al., 1998) (see appendix). Refer to section 1.4.3 for more details regarding the NCCPC-R. The checklist is translated to Norwegian and certified, but not yet validated on Norwegian children. This data was used as a starting point for the interview. The master student viewed this as a tactic to support the parents' observations of the behaviors they observe and view as pain behaviors in their child. The parents were asked about how applicable the checklist was for their child, and if they would recommend implementing its' use in other environments their child attends.

#### **3.4.2 The interview**

Data was collected by using a semi-structured life world interview technique which aims to *"understand themes of the lived everyday world from the subjects' own perspectives"* (Kvale, 2009:27). A life world interview technique is said to be able to give a description of social interactions in their context, the activity in focus, who participated and how the interaction developed (Haavind, 1987). Haavind (1987) explains that by organizing an interview in this fashion, one opens for a variety of possibilities for the informant's interpretations and reflections over why situations occur and develop as they do.

A semi-structured interview follows an interview guide and gives room for changing the sequence of questions, how questions are formulated, and how much time and focus are chosen on the different themes (Kvale, 2009). Kvale's (2009) seven stages of an interview investigation were followed and encompassed: thematizing, designing, interviewing, transcribing, analyzing, verifying and reporting. I received help to test and improve an appropriate interview guide from a parent with whom I have had many years contact with through treatment of her child who has lived with pain. The final interview guide used in this project (see appendix V) included two main themes: pain behaviors and pains influence on activities of daily living in everyday family life. Each theme included several questions which I could ask my informants, to help shed light on my research questions.

Before the interview commenced, parents received information about this project and were reminded of the themes of focus for the interview. Informants were asked to tell about a typical 24 hour period in their family life encompassing their experiences and perceptions with pain in their child in naturally occurring activities of daily living in the family. Questions almost always came from a topic or a situation which informants introduced, to obtain further clarification and detail about their perceptions. Questions were presented in an open ended fashion, so informants could complete them from their point of view. The interviewer also spent time talking with the parents after the interview. Occasionally, the interviewer experienced that valuable information was exchanged in these periods yet they were not voice recorded and only possibly noted in the fieldwork diary. Immediate impressions of each interview, including important features and topics that arose were also noted in the field diary a short time afterwards. Kvale (2009) informs that this can provide a valuable context when analyzing the interview transcripts. After interviewing the parents of 5 children with severe multiple disabilities, it appeared as though no new information was generated and it was thus considered that data saturation was obtained.

Parents were interviewed together and I thought this positive for my project, since the focus is on how parents perceive pain in their child and how pain affects ADL. My focus was not on finding differences in their perceptions but on how parents together construct their reality of their everyday life. Their stories included both "I" and "we" positions, sometimes they complemented each others' sentences, other times they talked at the same time and completed sentences for each other. They checked with each other if they agreed, and also presented with different views of some situations. All interviews occurred at informants' homes, usually for

practical reasons, as most interviews were undertaken in the evening after work or after their children were asleep. I experienced the home as a good scene for the interviews, since parents stories could become more alive for me, as they pointed to where situations occurred.

### **3.4.3 The master students' position**

Kvale (2009) points out that there is an asymmetrical power relation, between the interviewer and the informant, and recommends that interviewers reflect about the role power could have in the knowledge developed under the interview. As an interviewer, I defined the scope of the interview, decided the topics of discussion, and decided which situations I would like my informants to describe more in detail. At the same time, I see my informants as having experience that I myself do not have, which means that they also have power in the interview situation. My informants decided what they would like to share with me as a researcher.

Ulvik (2007) describes a researcher as being positioned in regards to his or her informants. As a physical therapist, I represent one of the healthcare professionals my informants are in contact with. This could influence how they construct my role under the interview and the topics that they perceive I would be interested in hearing about. They may perceive me as one of the therapists they have had experience with, encompassing positive and negative views, or may see me as a potential helper or advocate. Other roles that I have such as: being a mother, female, and a person in the same age group as my informants can all influence the topics of conversation during the interview and the knowledge constructed there.

The objectivity obtained in an interview is described by Kvale (2009:243) as “*dialogical inter-subjectivity*”, where there occurs a negotiation of meaning between the interviewer and the informant through dialog producing objective knowledge of the social world of an informant. A negotiation of meaning may also occur between researchers or between those interpreting a phenomenon. The inter-subjective shared knowledge obtained from the interview may be influenced by a variety of factors, and a few of the factors are represented in the following diagram.

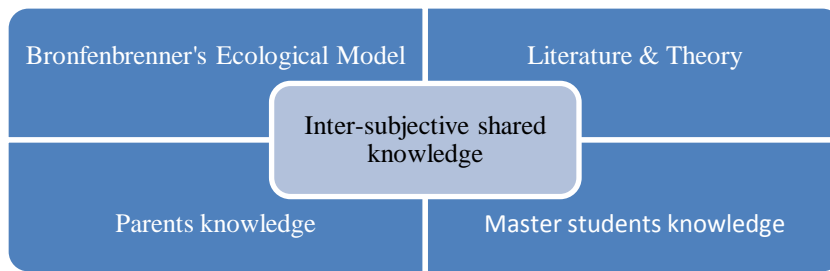


Figure 1: Relation between some of the factors that may influence the inter-subjective shared knowledge obtained from interview.

The family unit is in a mutual relation to other systems they are in contact with, such as school, respite, healthcare services, as encompassed in Bronfenbrenners model (1979). Parents’ relations with these systems may influence their experience with pain in their child, and their view of their social world. The parents and the master student also mutually influence each other through interaction during an interview, and the product of the interview is the inter-subjective shared knowledge developed (Brekke, 2006). This shared knowledge is influenced by several factors including the findings in the literature and the theory foundation the master student deemed relevant for this master project. These factors may influence interview questions, the analysis process and presentation of the results of the analysis due to their influence on how the master student views the topic.

### 3.5 Research ethical considerations

This study was approved by the Privacy Ombudsman for Research through the Norwegian Social Science Data Services (NSD).

Written and oral information about this project was given to both parents. Participation was voluntary and informed consent was obtained in writing. Parents were informed that they could withdraw their participation in this study at any time. All information was handled confidentially and participants are presented anonymously in the final report. Parents were informed of the possibility that the researcher may receive help to transcription and that a second reader might be used in the analysis of the data, and that their anonymity would be secured. The name list that connected the participants to a code list and the information gathered about the participants’ family were stored apart from each other, in separate locked cabinets. The audio-recorded and transcribed interviews were filed in a locked cabinet, where

only the researcher has a key, until the project is accepted and fulfills the requirements for completion of master program. These data will be maculated and erased at that time and latest by the end of December 2010.

The master student was aware that pain in a child and its' influence on the family could be a sensitive subject to talk about, and thought this could be especially true in the context of daily family life situations. The master student sought to be sensitive to the parents' histories and support them in any way possible. Parents' decided themselves how much they felt comfortable about sharing with the master student, and they were informed that they could chose to change the topic, take a break, or stop the interview at any time. As I undertook the interviews, I discovered that pain in their child was not a very emotional subject for parents to talk about. They had experienced pain in their child since they were small, and were used to living with pain in daily life. As one mother explained, "*You put your feelings aside to be able to cope.*" Parent's expressed satisfaction that someone was finally interested in hearing what they had to say about this subject, and who wanted to shed light on this very complex situation. The positive outcomes of this project, gaining knowledge about how parents perceive and communicate about pain and pain affects activities of daily living in everyday life outweighed the possible negative effects. When asked how parents experienced the interview situation, all reported it as being a positive experience.

### **3.6 Data analyses**

#### **3.6.1 Transcription**

The five audio-recorded interviews were of good quality and transcribed in full and close to verbatim by the interviewer, so that the master student could become intricately familiar with the recorded and transcribed interviews before the text underwent analysis. Ulvik (2007) supports this approach, since the interviewer has experienced the context of the interview and this can be positive for analysis. As Kvale (2009) explains, the analysis process of the meaning of what was constructed under the interview is already in process. By transcribing the interview oneself, the interviewer will learn about his or her own interviewing style (Kvale, 2009). When transcribing the first interview, I experienced that I may have been too eager to fill pauses with new questions. In further interviews, I became more secure with

pauses. These appeared to give my informants time to reflect over what they had said and new insights or more detailed descriptions followed.

### **3.6.2 Text condensing and reconstructing**

A phenomenological approach was chosen to analyze the data, to develop knowledge about parents' experiences with pain situations in children with multiple disabilities within the two themes of the interviews: how parents' perceive and communicate about pain; pains influence on activities of daily living in everyday family life. Husserl (1859-1938), who founded phenomenology, says that individuals must put aside their own viewpoints about phenomena to be able to see how it is experienced by others (Thomassen, 2006). Gadamer (1900-2002) points out a different perspective; that it is not possible to set aside our own viewpoints, because they provide the framework for what we notice and are able to understand from our own point of view (Thomassen, 2006). Our present is always connected to our past and our history. Using this perspective, a researcher must be aware of his or her own viewpoints about a subject and make them explicit for others. By being aware of them, a researcher can easier notice if his or her own viewpoints are the ones in focus or if the viewpoints of the informants are those in focus, and strive for the latter. By being aware of my pre-conceived views I can better put them aside in the interview situation and the analyses, and explore how parents experience pain and discomfort in the context of their everyday family life.

A thematic analysis, inspired by Giorgi (1975) was used as a process of systematic condensing of text as described by (Malterud, 2008, Kvale, 2009). Kvale (2009) presents this as a five step process: sense of the whole, extract natural meaning units, restate theme as understood by the researcher, interrogate meaning units, and reconstruct themes. The interview texts first went through a process of decontextualization and later recontextualization. Burr (1995) explains that deconstruction involves evaluating a text in a critical way, by breaking up a text to see how it is built up and to attempt to obtain its underlying meaning in (Askeland and Molven, 2006). In deconstruction, it is recommended to search for underlying meanings, dichotomy, and power relations that are revealed in the text.

Each interview was read through in full, to attain an overall view of what each informant shared with me. I noted my immediate thoughts about the interview as a whole, and key

issues I deemed important. The interviews were then read through several times, line for line, to find parent responses or natural meaning units that could shed light on my research questions. Parent responses went through processes of meaning condensation (Kvale, 2009). They were grouped and categorized into themes within each research question, through a process of data-driven coding. When working with coding, I had categories which went through many review processes to find out if they encompassed the same concept and could be grouped together. These coded categories went through further analyses through the use of theoretical perspectives and evidence on pain. In the last stage of the analysis, I went back to the original interview transcriptions to make sure that the perspectives of the parents from their own socially based interpretations are presented in light of theory and evidence presented in this project. Natural coding occurred in Norwegian. Themes were translated to English in the third stage of deconstruction where themes were restated as understood by the researcher. Only the parent responses referred to in this project were translated to English.

I began analysis of my first three transcribed interviews, which were completed with one week intervals, through the first two stages of text condensing. From these three interviews I noted similar meaning themes which were inductively derived from the transcribed interview texts including: ADL are painful, ADL are difficult, nighttime attention, difficult periods, knowing my child has pain, uncertainty regarding location and degree of pain, checklists, parents know child best. I conducted the next two interviews with heightened interests for the common themes. These two interviews went through steps one and two as the three previous interviews did, to see if new information was generated. All five transcripts were again individually read through line for line to extract natural meaning units to my three research questions. These went through further processes of analysis on the background of a variety of theoretical perspectives. This project involves two research questions, each involving different theoretical perspectives. These will be presented briefly in the next section.

### **3.6.3 Further analysis**

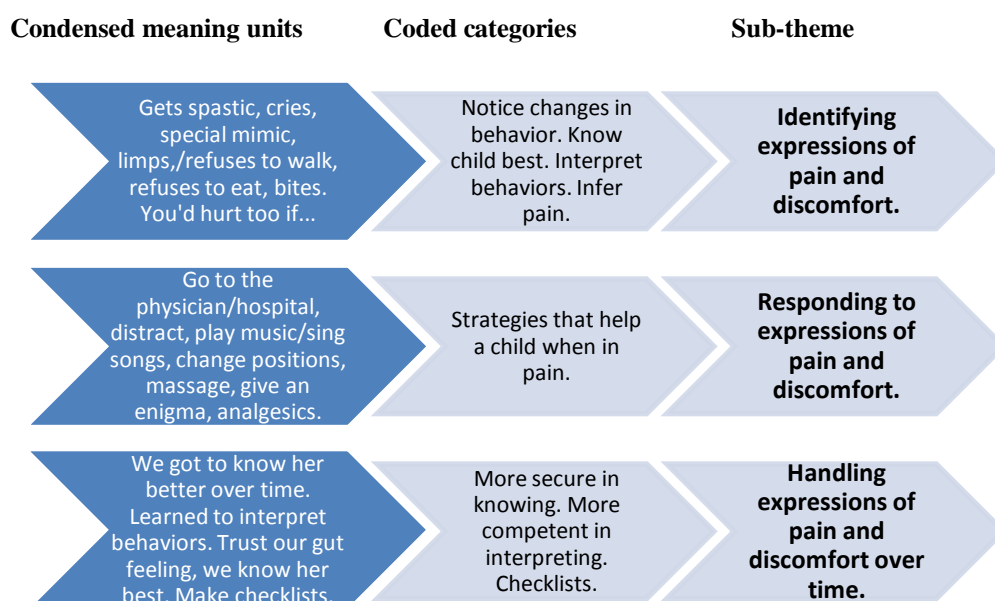
The first research question pertaining to how parents perceive and communicate about pain in their child with severe multiple disabilities was analyzed using symbolic interactionism. Symbolic interactionism was not used to guide codes, sub-themes and main themes, as these were derived from the data as mentioned earlier. As a perspective, it was used actively in



presenting the results of the data analysis as a way of understanding the realities of the parents in relation to the process of noticing, defining, interpreting and handling pain in their non-verbal child with severe multiple disabilities. Key words used that refer to symbolic interactionism will be: interaction, definition, interpretation, symbols, knowledge of past experience, and action.

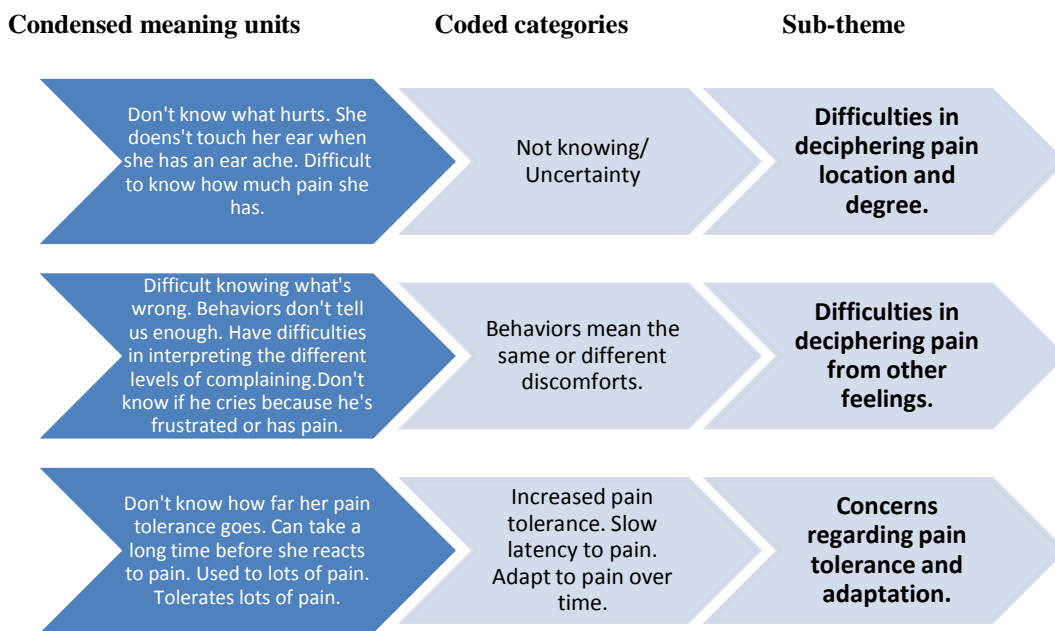
Interview data went through a process of noting the situation, the actors involved, the child’s behavior as observed by the parents, the parents interpretation or definition of their child’s behavior, parents actions to the behavior they defined in their child, and child response to parental action. Further analysis was guided by several questions including: how parents identify behaviors, what they identify, which behaviors are perceive as pain or discomfort, how they decipher what these behaviors can mean, which types of pain and discomforts they perceive in their child, what are the sources of pain, how do parents respond to pain, etc. The next to figures (2a-b) represent in short, the analysis process from condensed natural meaning units, to coding to sub-theme within the main themes “Exploring expressions of pain and discomfort” and “Challenges in deciphering expressions of pain and discomfort.

**Main theme:** Exploring expressions of pain and discomfort



**Figure 2a):** Process from condensed natural meaning units, to coding, to subtheme within the main theme of “Exploring expressions of pain and discomfort.”

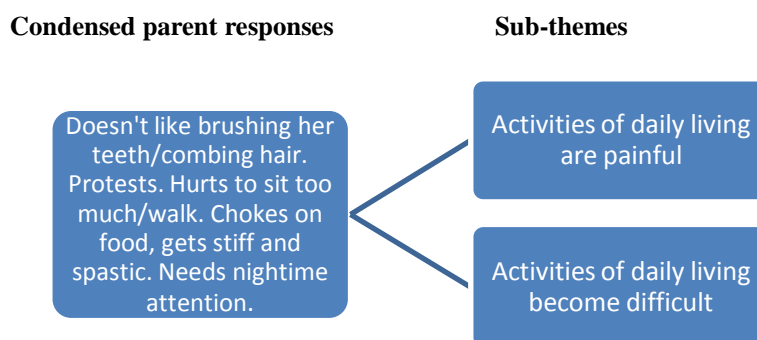
**Main theme:** Challenges in deciphering expressions of pain and discomfort



**Figure 2b):** Process from condensed natural meaning units, to coding, to subtheme within the main theme of “Challenges in deciphering expressions of pain and discomfort.”

Analysis of research question number two, which encompassed how pain affects ADL in everyday family life went through a process of noting activities of daily living, expressions of pain and discomfort parents observed during these activities, and how parents experienced that ADL. Analysis was further guided by questions regarding: which activities are perceived as painful or causing discomfort, and which activities were affected by pain and how? The process from condensed natural meaning units to sub-themes within the main theme “Pain affects activities of daily living negatively” is represented by the next figure (2c).

**Main theme:** Pain affects activities of daily living negatively



**Figure 2c):** Condensed natural meaning units to coding of subtheme within the main theme of “Pain affects activities of daily living negatively.”

### **3.6.4 Reliability and validity of the analysis**

The completed transcripts were checked against the original audio-taped interview, to make sure that they were as close to accurate as possible. Throughout the analysis processes I constantly went back to the original transcribed interview text to check that categories represented the perspectives of the parents to improve reliability of the results of the analysis. In the third stage of test analysis, I went back to each audio recorded interview to become more aware of the context and atmosphere of each interview. These gave meaning to the transcribed interviews, since analysis and interpretation are said to rely on the context (Brekke, 2006). I also focused on noting subtle changes in voices, interpreting feelings I could depict in their voice, words parents accentuated, and paid closer attention to pauses and noted them on the transcription. To further strengthen the reliability of the analysis process, I included two objective readers into the analysis process, who read two to three transcribed interviews each and discussed major themes and sub-categories. This was decided as necessary to reduce the possibility of researcher bias, since I have worked as a physical therapist with children with severe multiple disabilities and naturally have my own pre-conceptions about pain in this population. Reliability was also checked during interviews, by asking parents if I had interpreted them correctly.

### **3.6.5 Limitations**

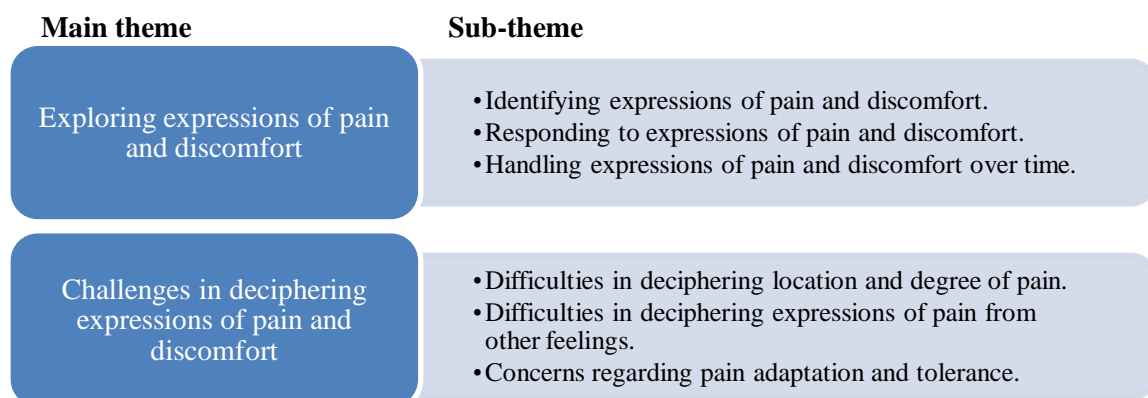
This project collected information from a small sample from a geographical area which spread over 2 neighboring counties in Norway. There is the chance for selection bias due to the recruitment process, which relied on parents' willingness to participate in an interview telling about their life experiences with pain. The data is based on retrospective accounts of parents' experiences with pain in their child, thus there is a chance of recall bias. Yet, these situations occur many times a day, over many years, and I view this as a good reason to believe that parents recall accounts have greater reliability and validity. Data are also based on parent proxy assessments of their child's pain and may not be truly representative of the child's subjective experience. To date, there are no valid subjective assessment measures for pain in children with severe communicative, cognitive and motor impairments. The focus of this project was on the parents' experiences with pain in their child in daily family life, and not on the child's experience.

## 4.0 RESULTS

In the next section, I will present main themes and sub-categories as developed from the analysis of the transcribed interviews. Excerpts from the transcribed interviews are used to depict the perspectives of the parents. I have not used direct quotations since parent responses were translated from Norwegian to English, and thus may not be an exact translation. Some responses are edited so they can be read with better flow. All parents are represented in the results, and responses are noted with M= mother, F= father and numbers 1-5 since there were five families included in this project. Parent responses are written in cursive.

### 4.1 Perceive and communicate about pain

Two main themes developed in regards to how interviewed parents perceive pain in their child: “Exploring expressions of pain and discomfort” and “Challenges in deciphering expressions of pain and discomfort”. The first theme includes three sub-themes: identifying expressions of pain and discomfort, responding to expressions of pain and discomfort, and handling expressions of pain and discomfort over time (see figure 3a.). The second theme includes three sub-themes: Difficulties in deciphering the location and degree of pain, difficulties in deciphering pain from other feelings, and concerns regarding pain tolerance and adaptation (see figure 3b).



**Figure 3a):** Main and subthemes regarding parents perceiving pain in their non-verbal child with severe multiple disabilities.

#### **4.1.1 Main theme: Exploring expressions of pain and discomfort**

Exploring expressions of pain and discomfort occurs during interaction between parents and the child by noticing their child's behavior, exploration of the meaning of these behavioral expressions and explorations of their child's needs. It is proposed that this requires caregivers who know a child well and who can notice and interpret their cues (Carter et al., 2002). It is important to point out that parents interpret their non-verbal child's behavioral expressions or appearance and this may not be exactly the same as the child's own view point. Parental competency in observing and interpreting behavioral expressions appears to develop over time with experience in handling expressions of pain and discomfort, a finding also presented in Ståhle-Oberg & Fjellman-Wiklund, (2009).

#### **Sub-theme: Identifying expressions of pain and discomfort**

##### Strategies used to identify pain

In order to identify pain or discomfort in a non-verbal child with multiple disabilities informants reported using their child's behavior and temperament to notice how their child felt or if there was something wrong. The parents defined or interpreted their child's behaviors or appearances and these became significant symbols when they mean the same for interacting partners. Through interaction with their child, the parents noted changes in produced sounds, behaviors, social interaction, activity level, or child's usual state as depicted here: *She was taking some medicine and all of a sudden she became acute lethargic. We are used to when we brush her hair that she doesn't like it; but then she just didn't react as usual. We could notice by a change in her behavior that something was wrong (M3)*. In this excerpt, a subtle change in this child's usual behavior, not reacting to her hair being brushed, became a symbol to her parents depicting that something was wrong and they sought medical attention.

Interviewed parents reported using their own experiences and responses to body discomfort to help them interpret their child's expressions, as also found in Hunt et al, (2003). One informant expressed: *She has a leg length discrepancy, and she limps pulling her whole body with it. I think that you'd notice it yourself if you walked so crooked. It must hurt after awhile (F3)*. By taking on the role of their child, informants imagined how they themselves would feel to help them understand their child's feelings. This involves emotional inter-subjectivity,

where parents empathize with their child in affect and content, yet they cannot feel exactly like their child, as described by others (Charon, 2001, Røkenes & Hanssen, 2006, Stern, 1985). Another informant explained about another tactic: *One time she fell when she crawled, and two teeth got knocked out with their roots. She cried to begin with and then wept for maybe five minutes all together, and then it was over. But, what we experienced with her back was much worse, so it had to be a lot more painful for her (F1)!* These parents noted a combination of behaviors in their child when they noticed that she had developed scoliosis including: *drooling, biting more on objects, lack of appetite, withdrawal, rejecting contact and crying with tears.* Excerpts like the previous one depict informants relating knowledge of their child's behavior from a past experience to a new situation to help interpret pain intensity.

Informants expressed concerns about other caregivers not being able to interpret their child adequately, as depicted here: *I'm his mother and know him best. It concerns me that he may suffer pain because other caregivers don't understand him (M2).* Interviewed parents perceived that their child was in need of their expertise regarding interpreting the child's behaviors and needs, as one informant explained: *They are very vulnerable when they can't communicate. They are reliant on their parents' or someone who knows them well, who cares about them and can interpret their cues (M1).* This excerpt expresses a view that these children need parents and caregivers who engage in an emotional interaction with them and tune into their child's experience through affective intoning as described by Stern (1985) (Hansen in Gulbrandsen, 2006). One informant described this tuning into her child as: *He's always an extension of my body, and needs me close to him (M4).* This excerpt can depict the symbiotic nature of this parent-child relation, where the child was perceived in close connection with his mother, in need of her expertise to interpret his appearances to understand his needs through interaction.

Interviewed parents expressed concerns that other caregivers may not notice or understand their child's behaviors, which may result in unnecessary pain experiences. One informant explained: *This past fall, I noticed bruises on her legs. And the personal on the bus said that she cried and didn't want to go into the bus. When they began to look at the situation, they noticed that another child was kicking her the whole way to and from school. Crying was a way to let others know about a painful situation (M1).* This excerpt depicts that the context in which a behavior occurs plays an important role in adequate interpretation of its meaning, a view supported by others (deGelder et al., 2006, Levin & Trost, 2005).

### Expressions of pain and discomfort

An abundant number of behaviors or appearances in a child were perceived by the parents as representing pain or discomfort. These behaviors included: emotional expressions, body language, facial expressions, sounds, and changes in moods, normal state, and ADL, also found in Ståhle-Oberg & Fjellman-Wiklund, (2009). Seven behaviors were noted as being mutual for depicting pain and discomfort: *cry/scream, whining/cranky, less appetite, special facial expressions, withdrawn, less physical activity/passive*, and a *combination of behaviors*. These behaviors are also reported in other studies (Breau et al, 2001, McGrath et al., 1998, Stallard et al., 2002b). A child's behaviors or appearances functioned as symbols for informants when their meaning was significant for representing pain and discomfort. Informants also mentioned a variety of other behaviors that appeared specific for depicting pain in their child. Several behavioral expressions parents described will be presented further.

### Facial expressions

Through interaction with their child, informants noticed changes in facial expressions such as the eyes opening wide or closing, a special look in the eyes or face, or a wrinkled forehead and these became symbols for them depicting pain. The important role of facial expressions in the social communication of pain is reported elsewhere (Deyo, 2004). Informants reported observing a special look in their child's eyes or face; calling this *a scared look, a more concentrated or frantic look, or a contorted face* and this became a symbol meaning that their child was scared or had much pain. A screwed up and distressed looking face had the strongest correlation with the presence and severity of pain in a similar population (Stallard et al., 2002b).

### Cry

Interviewed parents' perceived that intense crying in their child meant that something was very wrong, as one informant replied: *The first time she had extreme stomach pains, I went to the hospital with her. She screamed intensely (F5)!* Another informant explained: *I can interpret when he has a lot of pain, because he cries intensely or screams, and he doesn't usually do that otherwise (M2)*. Crying or screaming appeared to be a symbol depicting pain for all informants, which was a similar finding in McGrath et al., (1998) where more than 80% of caregivers reported cry and moaning as descriptive of pain. Informants reported understanding the degree of their child's pain due to the intensity of their crying. Yet, crying could also mean a variety of different emotions, such as *hunger, despair or frustration*.

### Combination of behaviors

Informants reported observing a combination of behaviors when there was something very wrong with their child or when they were perceived as experiencing much pain, a finding supported in another study (Stallard et al., 2002a). One informant described a combination of behaviors as: *When she has a lot of discomfort, she'll show many different behaviors like grinding her teeth, tramping with her foot or hand, complaining, and whining (M3)*. The children, who generally had self-stimulating or compulsive behaviors, were reported by their parents to present with more intense behaviors when they had pain and discomfort. These behaviors included *hand activity, finger activity in the mouth, hitting body parts* such as their head or thigh, *bumping their head on objects, rhythmic tramping, pulling or eating hair*, etc.

### Idiosyncratic behaviors

Some informants' perceived that idiosyncratic behaviors depicted pain, a finding supported in earlier studies (Breau et al., 2000, McGrath et al, 1998). An interviewed mother and father described an idiosyncratic behavior in their child as: *After a seizure, she can lie stiff, stretching her whole body. She crosses her arms straight in front of herself and presses down (F3). It's not a spasm (M3). No, it's a way to try and move the pain somewhere else (F3). Or a form for self-stimulation, to distract herself from the pain (M3)*. A few informants mentioned perceiving that seizures caused pain in their child due to severe muscle spasms, paralysis, bodily restlessness, strange body feeling, and suspected headache. Another informant (F5) informed that his child *throws her body violently backwards many times when she's sitting in her chair*, and this behavior became a symbol for her parents depicting pain. This included child also was observed to have a *seizure* in response to a painful event or she may *laugh* when experiencing pain. This behavior was very misleading to interpret.

### Passive/less physical activity/withdrawn

An informant described a passive/withdrawn behavior in her child as: *In a way, it was difficult to achieve good contact with her. It was like she was not really present (M1)*. Through attempts at interacting with her child and perceiving her as *withdrawn*, this behavior became a symbol depicting that she experienced severe pain from her scoliosis. Other descriptions of passive behaviors included: *doesn't crawl around and explore, sits still biting on toys, and does not engage in play/activities that she usually enjoys*. A child may attempt to control pain by reducing activity and social interactions, yet a withdrawn behavior or sleeping may also be misinterpreted as no pain (Merkel and Malviya, 2000, Breau et al., 2007).



### **Sub-theme: Responding to expressions of pain and discomfort**

Through interaction with their child, interviewed parents used a variety of techniques to try and help their child to feel better including: distraction, massage and body contact, take a bath, and pain medications. Singing songs and playing music appeared to be the most helpful distraction techniques. Playing with water and taking a bath were other activities that could help a child feel better when something was wrong. One informant explained about using a special blanket which encompassed his child's body and could help her relax if she wasn't too restless in the middle of the night. Sometimes distraction techniques could be very helpful, yet one informant explained: *We felt that everything we tried was just a waste of time. It didn't help at all. We believed that to mean that she had pain all of the time; that the pain was so bad that it was impossible to distract her from it (M1)*. Whether or not a child could be distracted helped informants decipher how much pain their child had.

Informants reported that some children wanted close interaction and contact with their parent when they had pain or discomfort, including cuddling and caressing, a similar finding in (Kankunnen et al., 2002). One informant replied: *She likes to be caressed under her feet when she has discomfort. If she's very restless, this can help her relax (F5)*. Massage often helped a few of the children feel better when they had discomfort, as also noted in (Russo et al., 2008). Through interaction with his child, this informant reported learning over time that certain techniques could help his child feel better. Another informant perceived that her child occasionally wanted to be left alone to relax in bed with a pacifier or music. None of the informants reported receiving help from professionals regarding non-pharmacological pain alleviation methods. Most informants reported administering over the counter pain medication (Paracetamol and/or Ibuprofen) to their child, perceiving their effect to be little to variable. It appeared as though several informants administered over the counter analgesics only as a last resort, possibly due to knowledge from past experience that these may only help their child be a little more relaxed. Hunt et al., (2004), also found that not all children in their study received adequate relief from analgesic administration, suggesting that the dose was insufficient or that treatment was not optimal for the type of pain experienced.

## **Sub-theme: Handling expressions of pain and discomfort over time**

### Increased awareness in practical knowledge and competency

Informants reported acquiring knowledge and increasing confidence over the years in recognizing and interpreting their child's cues, as represented here: *Something we have experienced all these years with our child is that we trust our "gut feeling" (M1)*. The importance of time to develop this competency was reported by the informants in this study and in others (Carter et al., 2002, Ståhel-Oberg & Fjellman-Wiklund, 2009). Competency in interpreting and handling a child's expressions of pain and discomfort appeared to develop in a dynamic process involving informants defining their child's behavior/appearance, acting on that definition, a child's actions to parents' actions, parents' redefining behaviors and new actions. Knowledge of past experiences of success and failure in interpreting their child's behavioral expressions and attending to their needs was used in new interpretations of their child's present behavior.

### A child's behaviors become more distinct over time

Interviewed parents perceived that their child's behavioral expressions had increased in number, and became more distinct and varied over the years. One informant explained: *His behaviors have gotten more distinct, especially when he's angry, in despair, or has pain. Now he has tears when he cries, earlier he just complained a lot (M4)*. Later in the interview she explained: *He's gotten better at moving his body part away and I can really see that it hurts in his facial expression*. Mead pointed out that individuals actively perceive, define and manipulate their environment to achieve goals (in Charon, 2001:132). Thus, these excerpts may depict that the children have learned, through a process of socialization through interaction over time, about responses they can expect from their caregiver to a given behavior. The child may then adjust his or her behavioral expressions or develop new and more distinct behaviors to better express their views and influence more appropriate action from caregivers to satisfy their needs, a view supported in other studies (Breau et al., 2000, Cramber-Berness 2007 in Riddel & Racine, 2009).

### Parents develop checklists

A mother and father had developed a checklist depicting exploration of their child's behavioral expressions of discomfort: *Does her stomach hurt? Has she been to the toilet lately? Is her bottom sore, does she have excrement there? Is she hot, does she have a fever or*

*an infection? Does she have a sore throat? We smell her breath. Does she have an earache? Has she bumped herself? Does she have a rash that itches? Does she have bruises, has she fallen?* (M/F5) Informants developed mental checklists which they went through as a process of elimination, to try and figure out what the problem was and how they could help their child, also reported by others (Carter et al., 2002, Hunt et al., 2003). Checklists include behavioral symbols of pain or discomfort. Checklists often included basic needs such as: hunger/thirst, diaper change/toileting, burp, change positions, contact, tired, wants to play etc. Informants also checked their child's skin for bruises, smelled their ear or throat or took their temperature to see if they had an infection. A checklist functioned as a helping aid representing parents increasing competency with interpreting their child's behavioral expressions and appearances. One informant explained: *Does her stomach hurt? Has she really emptied her bowels lately? That's the first thing we think about* (M3). This informant learned from past experience that the checklist had a starting point, which usually was related to her child's gastrointestinal system.

When informants could not find a source to the problem, they wondered if their child had a bladder infection or a toothache, and they contacted a doctor or dentist. Informants were concerned that their child possibly experienced pain and discomfort from cavities. *She had a long period with lots of troublesome behavior. Then, her two front teeth fell out and we noticed a cavity between them. After that, she was content again* (F5). An informant explained about concerns regarding dental visits: *She's never been to a thorough dental evaluation under anesthesia. The dentist only gets to look in her mouth for a few seconds and says everything looks good* (M3). This excerpt depicts this parents' view that it was difficult to get her child to cooperate with dental exams, a finding noted in a study (vanDijk et al., 2009).

#### **4.1.2 Main theme: Challenges in deciphering expressions of pain and discomfort**

Deciphering expressions of pain and discomfort can be challenging for parents regarding locating pain and understanding the degree of pain a child may experience. It also involves instances of success or failure in interpretation of a child's behavioral expressions. Deciphering behavioral expressions of pain and discomfort involves a dynamic process involving: defining behaviors, acting on the basis of this definition, evaluating the others

response to the action, and redefining symbols and new actions based on these interpretations (Levin & Trost, 2005).

**Sub-theme: Difficulties in deciphering the location and degree of pain**

Informants explained about behaviors that were difficult to decipher. One interviewed mother and father explained: *After a seizure, she can lay there stiff with her arms straight and crossed in front of her and pushing down. She self-stimulates in a way, and we think she has pain or discomfort. We wonder if she has a headache from all her seizures and how much it hurts (F3). Her behaviors don't tell us enough to really know, we just don't know (M3).* As depicted here, changes in their child's behaviors achieved their attention and they perceived that she possibly experienced discomfort. Yet, her behavioral expressions were indirect and did not give them information about the location and degree of discomfort she possibly experienced. This bodily expression was a symbol for her parents, depicting pain and discomfort. Due to contextual cues, such as observing this behavior after a seizure, these parents wondered if she had a headache or bodily pain from strong muscle spasms. Observing this behavior in other instances not related to a seizure, could be interpreted as discomfort from constipation. This highlights the special situation informants' are involved in, regarding interpreting their child's behaviors in everyday contexts, where the context plays an important role in appropriately interpreting expressions of pain and discomfort (deGelder et al., 2006).

This same informant described: *When it's diffuse, and she comes home and just sits there with her eyes closed and wrinkles her eye brows. And she won't eat. They are not active symptoms, but we interpret them to mean that something is wrong (M3).* A passive/withdrawn behavior became a symbol for this parent who interpreted it to mean that something was wrong. Yet, it was diffuse since she did not show active symptoms. This behavioral expression did not help her locate the problem.

**Sub-theme: Difficulties in deciphering pain from other feelings**

Informants reported difficulties in differentiating pain and discomfort from other feelings such as hunger, anxiety, or frustration, as also reported by others (Nolan et al., 2000, Ståhle-Oberg

& Fjellman-Wiklund, 2009). When asked if their child used different behaviors for different types of pain and whether informants could decipher these, one informant responded: *He cries if he's in despair or if he has pain. But, I don't always understand if he has pain, or if he's in despair, or if it's because he doesn't understand the situation (M4)*. Another informant replied: *Our child can cry and be stressed or cry because she's not satisfied, or she can be real quiet and passive. Maybe the different behaviors are for the same reason sometimes. I feel it's really difficult to know (M5)*. From excerpts such as these, crying was a symbol for both informants yet its' meaning or interpretation could be different. Informants explained of several factors that could complicate interpretations of expressions including: one behavior could mean different types of discomforts and emotions or that included children could use a variety of behaviors for a certain discomfort.

One interviewed father informed about behaviors that were difficult to interpret, explaining that: *She wakes up sometime between 3-5 am. Some nights she's more restless and complains and it appears that she has a lot of discomfort. And I try to calm her down. Sometimes she doesn't calm down until we move her into the living room, and she smiles. So, at times it can be really difficult to interpret what is wrong (F3)*. When this informant interacted with his child in the middle of the night, he found it difficult to understand the behavioral symbols she presented with. This informant first interpreted his child's behavior as pain, yet attempts at comforting her could at times prove worthless, depicting possible failure in interpretation. When the child was removed from the situation she became content, representing a new and possibly more correct interpretation of her behavior. This depicts the dynamic process of defining symbols, acting on definitions and redefining them in social interactions.

The issue of being able to distract a child, who appears to have pain and discomfort, could also challenge interpreting the presence and degree of pain, as one informant experienced: *He hasn't liked being transported to and from school in the bus the past year, and we can't figure out why. He cries the whole way and is totally exhausted when he gets home. We found out that if he listens to music he calms down. And then I wonder, can he have pain or discomfort if he can be distracted (M2)?* Music helped this child calm down and possibly forget his pain or discomfort, at least for awhile. Healthcare professionals reported that distraction and activity changes can be effective behavioral pain modalities (Oberlander & O'Donnell, 2001).

### Periods of time involving behavioral expressions of discomfort

Some informants informed about periods of time lasting several weeks or up to one year, where their child often presented with behavioral expressions of discomfort. Informants reported difficulties in deciphering their child's behaviors and resolving the problem during these periods, which they called *difficult periods*. A few informants' believed that epilepsy was the cause for these *difficult periods*, as their child often presented with increased epileptic activity. Yet, some informants also reported perceiving that pain, either physical or psychological, may also be a reason for these difficult periods. One informant expressed his views about his child's past *difficult period* as: *What she had this past fall; I really don't think that there was anything wrong physically. I think it was something psychological, but that's also a form for pain. But, we just couldn't figure out what's wrong and why (F1)*. On the background of past experiences with not finding a concrete physical source to his child's behavioral expressions during a difficult period, this informant redefined the situation to mean his child suffered from something painful psychologically. As noted earlier, pain and low cognitive functioning are reported as risk factors for psychological problems (Parks et al., 2008).

### Expressions of psychological pains

Some included parents perceived that their child experienced a variety of psychological or emotional pains, which Mee et al., (2006:681) has defined as "*an internal response to noxious psychological stimuli*". One informant described the everyday pains her child experienced as: *It's mostly about psychological things. He gets exhausted from transitions, and not understanding what's happening or when there is too much noise. I think he experiences pain and discomfort when he gets over stimulated (M4)*. This informant reported observing pain behaviors during these situations, including: *whining/complaining, biting on fingers/hands/clothes, hitting his head with his hand*. Some informants explained about situations they perceived which could be psychologically or emotionally painful for their child such as: *not being interpreted adequately, not having their needs understood and met, being exposed to too much noise, not understand what was happening and transitions between places*. Informants described expressions of psychological pains in a variety of terms such as: *exhaustion, despair, frustration, anger, jealousy, fear, panic, anxiety and depression*.

### **Sub-theme: Concerns regarding pain tolerance and adaptation:**

Most informants perceived that their child tolerated pain, as one informant explained: *Some nights she gets her foot caught between her mattress and her bed rails, and it can take a long time before she begins to cry. Her foot is blue and cold when we attend to her (F5)*. Another informant explained: *She bumped her little toe when she was walking, and she reacted just a little. She forgot it quickly and kept on walking. I thought to myself- If I had done that, I would have complained a lot longer. The pain probably lasted longer, but she just accepts it (F3)*.

Excerpts such as these may represent children being perceived as having a high pain threshold, which was also reported in similar child populations (Carter et al., 2002, Fanurik et al., 1999, Ståhle-Oberg & Fjellman-Wiklund, 2009).

Some informants reported perceiving that pain had been a part of their child's everyday life, by responses such as: *She's a child who has had pains all of her life and has gotten used to it (M3)*. *He has learned to live with lots of discomfort and everyday painful procedures, and seldom complains with stuff like that anymore (M2)*. Some children were perceived by their parents as having been exposed to pain all of their life and they seemed to have learned to live with it, a similar finding in Carter et al, (2002). A child having a high pain tolerance or adapting to pain was concerning for the parents since they do not really know how much pain their child tolerates. The possibility of adaptation to accidental pain over time was noted in a similar study population in Breau et al., (2003a), who also suggested that children may develop a greater sensitivity to non-accidental pain over time. Pain behaviors have been reported to habituate or dissipate over time in chronic pain (Chambliss et al., 2002, von Baeyer & Spagrud, 2006). There appears to be a need for more theoretical knowledge regarding pain development and pain adaptation in this population of children, as lack of knowledge may cause frustration and feelings of uncertainty for families (IS-1692:27).

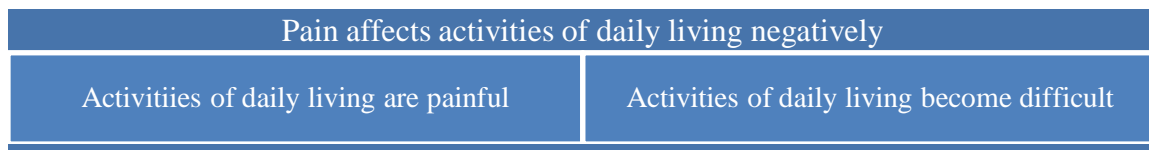
### **Ending comments**

None of the informants reported being aware if professionals used standardized behavioral checklist assessment to evaluate pain in their child. When asked for feedback regarding the NCCPC-R pain checklist, all informants responded that they recognized many behaviors in their child and felt it would be useful at school and respite. Children, whose parents scored

their behaviors on the NCCPC-R, presented with total scores above the cut off score of 7 which depicts the presence of pain in a child.

#### 4.2 Pains affect on activities of daily living

Through analysis of the interviews one main theme evolved in response to how pain affects activities of daily living in everyday family life: “Pain has a negative affect on activities of daily living”. This theme was further divided into two sub-themes: “Activities of daily living are painful” and “Activities of daily living become difficult” (see figure 3b).



**Figure 3b):** Main theme and subthemes regarding pains affect on ADL.

**Main theme:** Pain affects activities of daily living negatively

**Sub-theme:** Activities of daily living are painful

All informants reported pain in their child related to the musculoskeletal system, gastrointestinal tract, infections or accidents, which is a similar finding in (Breau et al., 2003). Painful ADL activities included eating, digestion/emptying bowel, walking, or hair grooming. When parents observed behavioral symbols of pain during an activity, they used a variety of techniques to try and distract their child and help them feel better so they could complete the activity, as described in an earlier section.

The majority of interviewed parents perceived that their child had encountered or currently encountered much pain from their gastrointestinal tract including their child: needing to burp, having gas pains, being bloated, and most frequently from constipation or having hard bowels, as noted in other studies (Carter et al., 2002, Oberlander et al., 1999b). Informants explained: *Her stomach often hurts. She has a lot of gas and gets easily constipated (F5). She had reflux the first years of her life, vomited blood and received two blood transfusions. She*



*must have experienced excruciating pain (M3)! One informant explained about her child's gastrointestinal tract affecting her child's general form as: When he eats and chokes it hurts and he gets stiff and spastic. When he's stiff he can't relieve gas or his bowels. And if he doesn't eat he can't fall asleep. So, these things need to function for him to be content (M2).* It was important that this functioned well and involved actions to help her child to relax during eating and emptying his bowels including: taking breaks, singing songs, and not rushing these activities. Informants perceived that regularly emptying the bowel was very important for all included children's general form and some often need help of an enema.

A few included children had a gastrostomy button where they received water, medicine and at times nourishment. One informant informed that: *He flinches and his eyes open real wide or shut tight. So, I can see by his facial expression that it hurts when it has to be cleaned (M2).* Thus, irritation of the skin around the button, cleaning the site and changing the gastrostomy button were perceived to cause pain in some of the children. Yet, this was also a situation where this informant perceived that her child had learned to live with the discomfort from cleaning the area, as noted in the section regarding adaptation to pain.

Walking with support was an activity that the parents perceived as causing pain and discomfort in a majority of the children. When one child refused to walk, her parents interpreted that walking may be painful for her due to her weight bearing on the insides of her feet. The parents imagined how it might feel to bear weight in this manner and thus inferred her pain, also reported in another study (Hunt et al., 2003). Another informant explained: *I notice more and more that she complains when she walks and she limps. So, I believe that she has a good amount of pain when she walks. When we ask the doctors about this they just tell us that scoliosis and her hip should not cause her pain. That we don't need to do anything with her hip until it causes pain (M3).* It appeared as though some informants did not experience that their view points, regarding their child's pain having a musculoskeletal origin, were acknowledged and taken seriously by physicians or specialists. This may be due to several factors such as: healthcare professionals lacking valid pain measures and having insufficient education (Malviya et al., 2005); or possibly due to beliefs and attitudes of healthcare professionals (Oberlander & O'Donnell, 2001, Schechter et al., 2003).

Some informants perceived that their child did not like having their hair brushed due to a hypersensitive scalp. One informant explained: *We bought lots of balsam spray, but it didn't*

*help. We just had to distract her, or else she just protested by shaking her head. I'm sure it must have been uncomfortable for her (F1).* This parents' definition of his daughters' behavioral expressions representing discomfort during grooming had consequences for his action. This parent tried balsam spray and tried to distract his child by singing. Another informant explained: *Regarding her hair, she's extremely afraid. When she sees her hair brush you notice that her shoulders get tense (F3).* This informant interpreted his child's body language of her shoulders getting tense to depict fear. Through knowledge of past experience, this parent knew that his child protested to grooming hair.

### **Subtheme: Activities of daily living become difficult**

The parents reported that several activities of daily living in the family became difficult to engage in when a child had pain or discomfort including: sleeping, eating, hygiene, dressing, and physical activity/mobility. Interviewed parents reported that children reacted with protests and difficult behaviors which could be challenging for them to interpret. They could define protests as their child not liking the activity, being exhausted or the child had pain or discomfort and could not tolerate the activity. Further, I will present ADL in everyday family life and how informants perceived that pain or discomfort in their child could affect them.

#### Sleep

Sleep disturbances were reported in all the children, and its cause appeared multifaceted. A majority of the parents need to attend to their child during the night, help them relax and feel better, or their child woke up early. One informant observed body restlessness in her child due to pain at night, and explained: *He can be extremely tired, but his body just can't relax. And it's usually due to gas that he can't relieve (M2).* This child had body stiffness and spasticity and was reported to wake up many times a night, possibly due to a variety of sources of discomfort including: needing to burp, wet diaper, compulsive behaviors with hands, and in need of position changes, epileptic activity, etc.

Some informants were unsure if their child's sleep was affected by epilepsy or by pain, or perhaps both. One informant had difficulties deciphering if his child awoke from epilepsy, pain, or just wanting out of the situation, as noted in the section regarding "difficulties deciphering behavioral expressions". Yet, Hemmingsson et al., (2009) found that pain appears

to be the strongest contributing factor to sleep problems and need for nighttime attention. This same informant explained about his child waking between 3-5 am every night and needing attention, and informed that: *We have an extra bed in her room, so we can comfort her, help her relax and maybe fall back to sleep (F3)*. A few families reported that their child received medication to help them sleep, using a natural product only or a natural product in combination with a prescribed medicine. None of the informants reported pain being addressed and treated in their child, and this is alarming when studies show that most children began sleeping through the night when pain was assessed and managed (Chalkiadis, 2001).

Children's sleeping difficulties and need for nighttime attention affected their parents sleep, and most informants reported suffering from sleep deprivation periodically or often. The parents reported feelings of exhaustion, and having a lack of energy as found in another study (Hemmingsson et al., 2008). Sleep is proposed necessary for restoration, optimal physical and psychological functioning and survival (Lewin & Dahl, 1999), and sleep problems may be viewed as a major stress factor that can affect parents' daily lives and their health (Chu & Richdale, 2009, Hemmingsson et al., 2008, Robinson & Richdale, 2003, Wright et al., 2006).

#### Washing/hygiene and getting dressed

Informants explained that washing and getting their child dressed could be difficult when their child had pain or discomfort. The children responded by being stiff, kicking and hitting, making dressing difficult, as one informant explained: *We tried to wash and groom her, and she just hit and bit. We saw how crooked her back was, but her doctor said her back couldn't be causing her pain (M1)*. While interacting during hygiene and dressing these parents interpreted their child's protests to mean that she experienced pain from her scoliosis. These parents' actions to their child's behaviors included both parents needing to be involved, one to hold and distract their child while the other completed the activity. They perceived this situation as a frustrating for them all. This child's protests may represent increased pain reactivity due to experiencing intrusive caregiver behaviors when in pain, as described in (Din et al., 2009).

Some informants reported difficulties with oral hygiene, where their child protested and refused to have their teeth brushed, or only allowed to brush a very short while. Informants wondered if this activity caused pain or discomfort, or that their child may just not like the

activity. Informants responded to their child's protests by singing and distracting them, yet often felt that they could not provide their child with proper dental hygiene.

#### Eating/Feeding/gastrointestinal tract

A lack of appetite was often reported by informants when their child had pain or discomfort, as an informant explained: *She has refused food when she has pain, then we know something is really wrong (M5)*. Refusing to eat, by refusing to open their mouth or pushing food away, became a symbol for informants that something was wrong and that their child may have pain or discomfort. Lack of appetite is included in the NCCPC-R as a behavioral pain cue (McGrath et al., (1998), yet not as a core item predicative of pain (Breau et al., 2001, Stallard et al., 2002).

#### Physical activity/mobility

Physical activity appeared to be affected negatively when the children experienced pain and discomfort. Informants experienced their children to become *passive, not exploring their environment, just sitting quietly 'in their own little world' and self-stimulating, quiet complaining where she sits with her eyes closed, not participating in activities that are usually enjoying*. Informants reported their child refusing to walk when they had pain and discomfort, and their child participated less in mobility and needed to be lifted and carried.

## **5.0 Discussion summary and clinical implications**

Discussion will focus on central elements from the results of this project in regards to its two research questions: How do parents perceive and communicate about pain and discomfort in a non-verbal child with severe multiple disabilities? How does pain and discomfort in a non-verbal child with severe multiple disabilities affect activities of daily living in the family? Results will be discussed in their relation to possible clinical implications for practice and healthcare delivery.

## **5.1 Recognizing parent's expertise**

Based on the findings of this study, the parents appear to present with expert knowledge regarding knowing their child. I will further summarize the strategies parents utilize to notice and explore their child's behavioral expressions of pain and discomfort. I will also discuss how parents' competencies develop over time through interaction with their child and deciphering their needs.

### **5.1.1 Strategies parents utilize to explore expressions**

The majority of interviewed parents expressed having learned how to interpret and handle their child's behavioral expressions through trial and error over time, representing utilizing a heuristic problem solving approach, as noted in the literature (Hunt et al., 2003). The parents used a variety of strategies to explore and interpret their child's behaviors to attempt to understand what their child's expressions meant and what their needs were. These strategies included: interaction, role taking, comparison to past experiences, knowing their child usual state, mental checklists, etc. Through interaction with their child, the parents noticed and interpreted their child's behavioral expressions of pain and discomfort. These behavioral expressions become symbols of pain and discomfort when their meaning became significant. When a behavior symbolized pain, it enabled the parents to respond to their child's needs. The parents attempted to take on the role of their child, by empathizing with them in order to understand their emotional expressions (Røkenes & Hanssen, 2002). This also involved the parents using their own experiences and responses to body discomforts to help them understand how their child possibly felt. Parents' inferring that their child experiences pain was also recognized in a similar sample of children (Hunt et al., 2003).

Changes in a child's behavior alerted the parents that something was wrong, and was interpreted as possible expressions of pain or discomfort, both in this study and others (Carter et al., 2002, Hunt et al., 2003). Changes in behaviors were observed in emotional expressions, body language, ADL and usual state, etc. In order to be able to interpret these changes in behavior as symbols of pain and discomfort, the parents described a long process of learning through experience with exploring, interpreting and handling behavioral expressions over time. The parents' definition of their child's behavioral expressions as symbols of pain has

consequences for how they respond to their child, a process described in Levin & Trost, (2005). Interviewed parents also relied on checklists, as a process of elimination to help find the source of the problem, as noted elsewhere (Carter et al., 2002, Hunt et al., 2003). Checklists included behavioral symbols of pain from knowledge of past experiences with painful situations which help parents interpret behavioral expressions in the present.

### **5.1.2 The role of the context in interpreting expressions of discomfort**

Interviewed parents expressed challenges regarding deciphering the location and the degree of pain, and differentiating pain from other feelings, a similar finding in other studies (Nolan et al., 2000, Ståhle-Oberg & Fjellman-Wiklund, 2009). A finding of particular interest for further discussion is that the parents perceived that a behavioral expression or symbol could be interpreted as different types of discomforts and emotions depending on the situation the behavior was observed in. This supports the view that context plays an important role in deciphering pain expressions (deGelder et al., 2006). The parents observed and interpreted their child's behavioral expressions of pain in the context they occurred in during ADL in the family. Due to the important role context plays in the expression and interpretation of pain, it would appear that parents have the best possibility of knowing if their child experiences pain during these activities. The same behavioral expressions of pain that parents observe in their child at home may not be observed in other contexts, such as at the physicians' office or the hospital. This is a disturbing thought, since physician's conclusion about the presence and degree of pain in a child often forms the basis of decision makings regarding treatment. The role of context will be discussed further in implications for practice.

## **5.2 Pains influence on activities of daily living in everyday family life**

This current project sought to gather knowledge regarding which naturally occurring ADL in everyday family life interviewed parents perceived as being affected by pain as this did not appear to be elaborate on in other studies (Breau et al., 2007, Ståhle-Oberg & Fjellman-Wiklund, 2009). This knowledge may help guide pain assessment and management strategies, which in turn can help healthcare professionals provide services that better meet the needs of these families. Interviewed parents perceived that some ADL cause their child pain and that

ADL became more difficult when their child experienced pain, thus adding to the burden of caregiving. The burden of caregiving has received much attention in the literature the past 20 years (Barlow et al., 2006, Brehaut et al., 2004, Murphy et al., 2007, Raina et al., 2004). Yet, few studies appear to focus on pains affect on caregiving of children with disabilities.

### **5.2.1 Activities of daily living that may cause pain**

ADL that some of the parents perceived as painful events for their child included: eating/feeding or digestion, grooming/oral hygiene, and sitting and walking. Healthcare professionals also viewed these ADL as painful in a similar child population (Oberlander & O'Donnell, 2001). Transfers, lifting and carrying were not perceived as painful events by the majority of the parents in this current project, yet they were by 63% of the healthcare professionals in a similar study population (Oberlander & O'Donnell, 2001).

A finding of special interest in this project was that only a few informants mentioned the possibility of pain causing sleep disturbances in their child. This is surprising due to the number of studies suggesting that sleep disturbances are common in children with disabilities, with pain being the major cause (Chalkiadis, 2001, Hemmingsson et al., 2009, Wright et al., 2006). Several interviewed parents attributed their child's sleep disturbances to epilepsy. Deep stages of sleep involve the prevention of the perception of and response to pain signals (Lewin & Dahl, 1999). Thus, if a child has epileptic activity during the night then they possibly move into a lighter sleep stage and can be more aware of pain and discomfort. All included children were reported being treated for epilepsy, so informants may view night waking as something they must live with. If parents perceive that sleeping difficulties are part of their child's underlying condition, they may not seek medical attention for the problem (Chervin et al., 2001). Likewise, if healthcare providers do not assess pain in this child population on an ongoing basis pain may remain undiagnosed or undertreated.

The parents reported experiencing periods of sleep deprivation and exhaustion due to their child's sleep difficulties. Studies show that sleep disturbances in children with disabilities have a significant negative effect on parents sleep and their health and well-being (Hemmingsson et al., 2009, Robinson & Richdale, 2004, Wright et al., 2006). It was reported that almost all of the children with CP began sleeping through the night or that their sleep

quality improved when pain was adequately addressed (Chalkiadis, 2001). Thus, adequate assessment and management of sleep disturbances and pain in these children may have a positive effect on the health and well-being of the children and their parents, which is in line with family-centered care (Barlow et al., 2006, Wiggs & Stores, 2001, Wright et al., 2006). It appears that parents and healthcare professionals would benefit from more knowledge regarding how pain can affect sleep and sleep deprivations possible affect on the health and well-being of children and parents.

### **5.2.2 ADL become difficult when a child has pain**

ADL were reported to become difficult possibly due to pain or the child not liking the activity or being too tired. ADL that became difficult included: sleep, hygiene and dressing, eating/feeding/digestion, and physical activity/mobility. Parents reported difficulties in deciphering expressions of pain from other feelings, in this study and others (Nolan et al, 2000, Ståhle-Oberg & Fjellman-Wiklund, 2009). Thus, there is a possibility that parents may misinterpret their child's protests during ADL to mean that the child did not like the activity or was too tired for it, when the activity may in fact be painful for their child or exasperate the pain they may be experiencing from other sources. The parents' attempts at caregiving possibly were perceived by the child as irritating or intrusive, as was noted in another study (Din et al., 2009). Some of the children in this study may have increased their protests during ADL in an attempt to have their behavioral expressions acknowledged by their parent and their desire for comforting met.

The parents view of an ADL causing pain or a child not liking the activity has consequences for help seeking. Parents reported seeking medical attention when they perceived that their child experienced pain from the gastrointestinal tract, the musculoskeletal system, infections or ADL. Management of some of these pain sources may prove to be difficult, and not all can be completely resolved. A few informants expressed feeling that their concerns regarding pain in their child were not always taken seriously or that they were downplayed by their physician or specialist, a view point also presented in the literature (Hunt et al., 2003, Lerdal & Sørensen in von Tetzchner et al., 2008). The thought that their child may experience pain that goes undiagnosed and that their child suffers unnecessarily distressed them, a finding noted by others (Malleon et al., 2001). It appears as though the parents in this current study, over



time, perceived that pain was a natural part of their child's condition and that their child had learned to live with pain and discomfort, as noted in other studies (Carter et al., 2002, Ståhle-Oberg & Fjellman-Wiklund, 2009).

ADL becoming difficult due to pain is an interesting finding due to the implications this may have regarding parents seeking help. Interviewed parents did not report seeking assistance for difficulties they experienced in ADL. A few of the parents expressed views that professionals did not know their child or their situation and thus they did not perceive them as being in a position of being able to help them. The parents' views appear to support the importance of 'knowing the child' and the context a problem occurs in to understand their realities, a view expressed by (Craig, 2009, Hunt et al., 2003, Røkenes & Hanssen, 2006). Healthcare professionals may focus on other aspects of a child's healthcare and overlook ADL in the family, or they may wait until parents express difficulties and a desire to receive guidance.

### **5.3 Implications for practice**

There appears to be a need for more open communication between parents and healthcare professionals regarding ADL in the family and a child's sleeping difficulties. The results of this current study suggest that this is an area in need of improved management strategies to help lessen the burden of caregiving of a child experiencing pain, due to its negative effects on caregiver health, as noted in (Barlow et al., 2006, Brehaut et al., 2004, Murphy et al, 2007). Management strategies may focus on helping parents' master the challenges they experience in caring for their disabled child with pain, which is a goal of habilitation noted in the literature (Lerdal & Sørensen in von Tetchner et al., 2008). These strategies may include addressing the source of pain directly or by teaching parents alternate ways of assisting their child which may reduce a painful experience. These strategies may improve the health and well-being of the child and the parents.

#### **5.3.1 Acknowledging parents' role in pain assessment and management**

Children with severe multiple disabilities communicate through sounds, body language and behaviors. Interviewed parents viewed their child as *vulnerable and reliant on caregivers who*

*knew them well and who could interpret their cues*, a similar finding in other studies (Carter et al., 2002, Ståhle-Oberg & Fjellman-Wiklund, 2009). This finding supports the view that these children are dependent on supportive relationships with caregivers that know them well, so that their needs and wishes may be interpreted appropriately enabling them to influence their environment, as found in another study (Vlaskamp & van der Putten, 2009). Informants expressed developing competency in interpreting and handling their child's expressions of pain and discomfort over time through interaction, which is also a similar finding in other studies (Carter et al., 2002, Hunt et al., 2003, Ståhle-Oberg & Fjellman-Wiklund, 2009). Thus, the parents obtained specialized practical knowledge regarding knowing their child well through long term experience with interpreting and attending to their child's needs through interaction.

The findings of this study suggest that the practical knowledge the parents have makes them 'experts' in relation to interpreting their child's expressions and attending to their needs within the home context. As experts they handle their child's behavioral expressions "*intuitively, holistically, and synchronized*" as described by (Flyvbjerg, 1992:31). Informants perceived that their child was in need of their expertise regarding interpreting their behaviors and needs, and expressed concerns that other caregivers may not understand their child's behaviors and their child may experience unnecessary pain and discomfort. This can be viewed as parents' concerns that other caregivers may not be emotionally involved in their child and sensitive to their child's expressions. Both emotional involvement and affective attunement are viewed as necessary to be able to notice and interpret a child's behavioral expressions adequately (Stern, 1985). Another viewpoint is that informants may be concerned that other caregivers may not operate with the same behavioral symbols for pain in their child as they do. Behavioral symbols develop through interaction in a dynamic process of defining behaviors, acting on that definition, a child acting back, and redefining behaviors.

It appears that parents are best qualified to know if their child has pain and discomfort in the home context, since they know their child's baseline behavior and temperament, and can easily notice subtle changes in these areas, based on the findings of this study and others (McGrath et al., 1998). This ideology is in line with family-centered care, yet the findings of this study suggest that the parents' competencies were not always being acknowledged by healthcare professionals. On the basis of the importance context plays in knowledge attainment and in the expression and interpretation of pain, it appears that parents'

competencies should be given greater status in the assessment and management of pain in this child population.

### **5.3.2 Shift in power relations**

#### Shift in power relation

Viewing parents as experts will entail a large shift in traditional power relations between professionals and clients (Norman et al., 2006). Professionals' knowledge and objective findings have traditionally been prioritized as the best knowledge to base decision makings regarding treatment. Parents' practical knowledge develops through interaction with their child, involving them taking on the role of their child and understanding how they may feel and what their needs are (Lorentzen, 2006). A shift in power relations will entail professionals acknowledging parents as experts regarding their child, and place professionals in a position of learning from parents about their practical knowledge. It will also entail professionals taking on the role of the parent to understand their perspective, involving empathy.

This shift in power relations appears to meet resistance from some professionals and parents, and they are not always consciously aware of these relations (Skau, 2003). Some professionals may welcome this change. Yet, others may feel uncomfortable in a new role where they no longer have all the control, which may be viewed in terms of paternalism. Professionals may be resistant to no longer defining the professional-client relationship, which is described by (Schibbye-Løvlie, 2002). Likewise, not all parents may feel comfortable with being viewed as an expert. Parents have practical knowledge and know their child and the context a problem occurs in, yet they may not possess enough relevant knowledge regarding their child's diagnosis, the population and the science.

#### Sharing power

Skau (1999) informs that clients would like professionals to have a holistic understanding of their situation. To achieve this, professionals will need to get to know their clients requiring relational competency and effective communication skills. Røkenes & Hanssen (2006) propose an interactional communications model involving four perspectives: one's own perspective, the other's perspective, the inter-subjective shared experience and the interaction perspective. By utilizing this perspective, healthcare professionals must be aware of their own

perspectives regarding pain and make them know to the parents. They will need to learn about parents' practical knowledge and perspective on their child's pain in the context of everyday family life to understand its' meaning for them. Further, healthcare professionals and their clients can collaborate regarding their inter-subjective shared experience to find the mode of pain management that best fits the child's and the family's needs. The last perspective involves understanding the relation and interaction between both partners, by effective communication and reflection over what occurs in the interaction.

This communications perspective appears to be in line with interaction through shared power involving respecting the others field of competency: the clients, the professionals, and the shared experience (St. Arnaud, 1999 in Falardeau & Durand, 2002). In line with the philosophies of family-centered care, parents having a key role will involve healthcare professionals acknowledging this role, accepting and respecting parents' practical knowledge and supporting them to become more competent through information exchange (Dunst & Trivette, 1996). Professionals will also need to provide families with relevant theoretical knowledge regarding the nature and course of their child's diagnosis, what they may expect and treatment options to be able to share in decision makings (IS-1692:27). Yet, parents report that they have information needs that are not being met by professionals and service provision (Buran et al., 2009, Fisher et al., 2001, Murphy et al., 2007). It will also encompass the need for healthcare professionals to gain further knowledge regarding pain in children with special needs, pain assessment and management strategies a view supported in the literature (Karling et al., 2002). Increased knowledge and information exchange regarding pain may benefit both parents and healthcare professionals, which supports the need for further studies on this complex topic.

### **5.3.3 Partnership in adequate pain assessment and management**

A concerning finding in this study was that none of the informants reported being aware that pain was being assessed by healthcare professionals on an ongoing basis, and thus pain may go undetected and undermanaged in their child. This finding appears to support the risk of under diagnosis and under management of pain in this population, which is presented in several other studies (Hadden & von Baeyer, 2002, Roscigno, 2002, Ståhle-Oberg & Fjellman-Wiklund, 2009). The finding that pain is not being assessed actively on an ongoing

basis is disturbing given the amount of research claiming that daily pain is common in children with severe neurologic and severe cognitive impairments (Breau et al., 2003a, Oberlander & O'Donnell, 2001), and the relation between the severity of impairment and higher pain frequency in children with CP and cognitive impairment (Berrin et al., 2007, Breau et al., 2003a, Houlihan et al., 2004, Liptak et al., 2001). The parents reported administering over the counter pain medications and perceived their effect to be little or variable, a similar finding in Hunt et al., (2004). This finding supports the need for prioritizing an active and ongoing pain assessment in this population so that children may receive appropriate pain relief which is viewed as a human right by the IASP.

Craig (2004) proposed that how an individual perceives pain in another and how they act upon this perception can affect the other's well-being. With this in mind, parents 'expert' position of 'knowing' their child's usual state and being able to notice subtle changes, may mean that they have a key role in the diagnosis and management of pain in children, a view supported by Hadden & von Baeyer, (2002). Due to findings of this study and others already mentioned, regarding the importance of context in interpreting behavioral expressions of pain; it would appear that parents should be involved, to a larger extent, in the assessment of pain in the context it occurs in. This could involve educating parents in the use of standardized pain checklists that are validated for use in the home setting. Parents' assessment of pain in their child in the home setting would then constitute a pain history that could follow their child to school, respite, or doctor/hospital visits. This would encompass valuable information about a parents' perception of their child's pain experience in their context, and how their child expresses pain.

Due to the complex nature of pain conditions in this population, this appears to further supports the need for obtaining a multi-facet assessment of pain in this population, such as the one proposed by Hunt et al., (2003) including: 'knowing the child', 'knowing the population', and 'knowledge of the science'. By including parents into the assessment of pain, their knowledge could then be combined with the professionals' theoretical knowledge to aid in adequate decision makings. This will involve inter-subjectivity between the caregiver, the child and the professional to explore what the pain experience means for them (Hunt et al., 2003). In this manner, pain assessment and management strategies can become family-centered and better meet the needs of the family, and they may have the potential of enhancing their well-being (Brehaut et al., 2004, Raina et al., 2005).

## **5.4 Ending comments**

The findings in this project and knowledge presented in the literature, further support the recognition of parental competencies in the collaboration between parents and professionals in regards to assessing and managing pain in children with severe disability. Parents' practical knowledge should be given expert status that professionals can learn from, as supported in (Edwards et al., 2004). This project recommends parents becoming actively involved in standardized assessments of pain in children with severe disabilities. This would encompass assessing real life behaviors in the context of their natural environment by using valid pain assessments for this setting. By doing this, families experiences and competencies can be given the authenticity and credibility they deserve.

The results of this project further support the need for healthcare professionals to search for knowledge about how the child and his or her family experience and understand their situation from their social, cultural and historic context, as also supported in Bronfenbrenner (1979) and family- centered care philosophies. Healthcare professionals will need to investigate the needs of disabled children and their families in the context of their daily lives, involving assessing and understanding problems from the family's perspectives. Understand parents perspectives on pain in their child and its' perceived affects on the family, will assist healthcare providers to better custom design service provision to meet the intricate needs of families caring for severely multiple disabled children with very complex pain experiences. This is important when studies suggest that one of the strongest predictors of family well-being is their perception and experiences with family-centered professional support (Davis & Gavidia-Payne, 2009). Symbolic interactionism as a perspective may prove fruitful for healthcare professionals in learning to understand about pain from the perspectives of the family, by understand how parents define the situation, how they perceive their child's behavior and its meaning for them in the context of their everyday life.

## **5.5 Need for further research**

The findings of this project are based on a very small sample, and may only be representative for the area of Norway in which they were recruited. Yet, the findings were similar to other studies (Carter et al., 2002, Ståhle-Oberg & Fjellman-Wiklund, 2009). There is a need for

studies with larger samples to increase the generalizability of findings, and longitudinal studies to generate knowledge about pain and its' effects on the child and family over time. There appears to be a need for further studies regarding: parents and professionals perceptions of pain and how they influence pain assessment and management in children with neurologic and cognitive impairments; and pain managements affect on sleep quality and the health and well-being of the disabled child and their parents. Further knowledge may help develop treatment guidelines including diagnostic, treatment and follow-up care involving a team approach (see IS-1692:152). As proclaimed by the IASP, pain relief is a human right and children and their families deserve the best pain management possible. The findings of this project and findings in the literature support a need that pain in children with severe disabilities becomes a priority for all healthcare professionals.

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[http://pediatric-pain.ca/files/02/79/NCCPCPV\\_200901.pdf](http://pediatric-pain.ca/files/02/79/NCCPCPV_200901.pdf)

## **Abbreviations**

ADL	Activities of daily living
CNS	Central nervous system
CP	Cerebral Palsy
GMFCS	Gross Motor Function Classification Scale
IASP	International Association for the Study of Pain
ICF	International Classification of Functioning, Disability and Health
NCCPC-R	Non-Communicating Children's Pain Checklist- Revised
PICIC	Pediatric Indicator for Communicatively Impaired Children

# **Request for participation in the research project**

*"Pain in non-verbal children with severe multiple disabilities."*

*A qualitative study of parents perceptions about pain in their non-verbal child with severe multiple disabilities and how pain affects activities of daily living in the family.*

## **Background and purpose**

This is a request for you to participate in a research study designed to gain knowledge about living with a school-age child with multiple disabilities, who shows signs of discomfort or pain in everyday activities and tasks in the family. This project applies to children who have difficulties in communicating pain or discomfort, and whom are dependent on others to interpret their behaviors. The project seeks knowledge about how parents perceive and communicate about the child's pain and the impact the child's pain has on the family's everyday life. It is desirable, but not necessary, that both parents/guardians participate, together or separately.

This project forms the basis for a thesis in the Master's degree in rehabilitation at Oslo University College. The project leader is Karen Kleivene, Physical Therapist. Bjørg Fallang, Physical Therapist, Dr. philos., and associate professor at Oslo University College is appointed as supervisor of the project. The project is approved by the Privacy Ombudsman for Research through the Norwegian Social Science Data Services (NSD).

## **What does the study involve?**

If you say yes to participate in the study, it means that you accept to participate in an interview conducted by the master student in which you inform about your experience with the mentioned topics. The interview is expected to take approximately 1-1 ½ hours depending on whether one or both parents are interviewed at the same time. The interview will be conducted during early winter 2010, and will be audio-recorded for later to be written down. The interview can be completed at the student's workplace or in the participant's home. You will also be asked to fill out a simple checklist that maps the child's pain behavior, a few days in advance of the interview. You will be asked to fill out a form asking for information on the child's gender, age, diagnosis, number of siblings, and some information about parents, etc. before the interview is conducted.

## **Possible advantages and disadvantages:**

The purpose of this study is to increase knowledge about how parents experience caregiving of a child with pain or discomfort in everyday situations. This knowledge can help to improve service provision for pain in these children and their family. Participation should not cause any inconvenience to you, only the time you must use to participate in the interview. You

choose of course what you would like to convey and elaborate on, with how your child's pain affects the family's daily life.

### **What happens with the information about you?**

The information recorded about you will only be used as described in the purpose of the study. All information will be treated confidentially, without a name and identity number or direct recognition of you and your family. A code will connect you to your data through a list of participant names.

The list of participants is kept separate from the code list and all information. It is only the master student who leads the project that has access to the list of participants that can check back to you. If an assistant is used to write down the interview or read and help in the analysis process, you will be anonymous for this person. It will not be possible to identify you in the results of the study when they are published. The information and audio-recording will be maculated (shredded) and erased/deleted at the least by the end of 2010.

### **Participation is voluntary:**

Participation is voluntary in the study. If you wish to participate in the project, I request that you sign the agreement declaration on the last page of this letter, and return it in the enclosed prepaid envelope to the master student, as soon as possible. If you have any questions regarding the study, please contact Karen Kleivene at tel. 97184043. You may at any time and without giving any reason, withdraw your consent to participate in the study, by notifying Karen Kleivene.

### **Contact information:**

Karen Kleivene, master student

Klingremoveien 118

4877 Grimstad

[Karann4@hotmail.com](mailto:Karann4@hotmail.com)

Mob. 97184043

Björg Fallang, Supervisor

Dep. of Health Sciences. University College of Oslo

[Bjorg.Fallang@hf.hio.no](mailto:Bjorg.Fallang@hf.hio.no)

## Consent to participation in the study:

### **"Pain in non-verbal children with severe multiple disabilities and how it affects activities of daily living in the family."**

I agree that information about me can be collected from interviews and survey forms completed by me, and that they can be filed in a locked cabinet in which only the project manager has access during the project period.

I understand that participation in the project is voluntary and that I may, at any time, withdraw my participation and ask to have my information deleted.

I am willing to participate in the study.

-----  
(Signed by the project participant) (relationship to child) (date) (telephone)

Jeg er villig til å delta i studien. I am willing to participate in the study.

-----  
(Signed by the project participant) (relationship to child) (date) (telephone)

I confirm that I have given information about the study.

-----  
(Signed, role in the study) (date) (telephone)



## Forespørsel om deltakelse i forskningsprosjektet

### *”Smerte hos barn med multifunksjonshemminger og hvordan den påvirker familien.”*

#### **Bakgrunn og hensikt**

Dette er et spørsmål til deg om å delta i en forskningsstudie med hensikt å få kunnskap om det å leve med et barn i skolealder med multifunksjonshemminger, som viser tegn til smerte eller ubehag i hverdagslige aktiviteter og gjøremål i familien. Dette studiet gjelder barn som har vansker med å kommunisere smerte eller ubehag, og som er avhengig av at noen tolker dets adferd. Prosjektet søker kunnskap om hvordan foreldre oppfatter og kommuniserer om barnets smerte og de konsekvensene barnets smerte har for familiens hverdagsliv. Prosjektet søker også kunnskap om hvordan dere som foreldre/foresatte opplever å bli møtt av helsetjenesten og hvilke behov og ønsker dere har for hjelp og støtte når det gjelder barnets smerter. Det er ønskelig men ikke nødvendig at begge foreldre/foresatte deltar, sammen eller hver for seg.

Prosjektet danner grunnlaget for en masteroppgave i masterstudium i rehabilitering ved Høgskolen i Oslo. Prosjektleder er Karen Kleivene, fysioterapeut. Veilederen er Bjørg Fallang, fysioterapeut, dr. philos., og førsteamanuensis på Høgskolen i Oslo. Prosjektet er godkjent av Personvernombudet for forskning gjennom Norsk Samfunnsvitenskapelig datatjeneste (NSD).

#### **Hva innebærer studien?**

Hvis du/dere sier ja til å delta i studien, betyr det at du/dere deltar i et intervju ledet av masterstudenten hvor du/dere forteller om erfaringer og opplevelse med overnevnt tema. Intervjuet er beregnet å ta ca. 1-1 ½ timer avhengig av om en eller begge foreldre intervjues samtidig. Intervjuet vil bli foretatt i løpet av tidlig vinter 2010, og vil bli tatt opp på lydbånd for senere å bli skrevet ned. Intervjuet kan gjennomføres på studentens arbeidsplass eller i deltagerens hjem. Du/dere vil også bli bedt om å fylle ut et enkelt avkryssingsskjema som kartelegger barnets adferd ved smerte eller ubehag, et par dager i forkant av intervjuet. Du/dere vil bli bedt om å fylle ut et skjema med informasjon om barnets kjønn, alder, diagnose, antall søsken, deres alder. osv. før intervjuet gjennomføres.

#### **Mulige fordeler og ulemper:**

Hensikten med dette studiet er å øke kunnskapen om hvordan foreldre opplever det å ha omsorg for et barn med smerte eller ubehag i hverdagssituasjoner og de erfaringer og behov de har i forhold til hjelpeapparatet. Dette kan bidra til å utvikle tjenesteytingen på dette området. Deltagelsen skal ikke føre til noen ulemper for dere, bare den tiden dere må bruke for å delta på intervjuet. Du/dere velger selvfølgelig hva dere ønsker å formidle og utdype om hvordan dette påvirker familiens dagligliv.

#### **Hva skjer med informasjonen om dere?**

Informasjonen som registreres om dere skal kun brukes slik som beskrevet i hensikten med studiet. Alle opplysninger vil bli behandlet konfidensielt, uten navn og fødselsnummer eller

direkte gjenkjenning av deg og din familie. En kode knytter deg til dine opplysninger gjennom en navneliste.

Navnelisten blir oppbevart adskilt fra kodelisten og all informasjon. Det er kun master studenten som leder prosjektet som har adgang til navnelisten som kan finne tilbake til deg. Hvis en medhjelper brukes for å skrive ned intervjuet eller som hjelpeleser i analyseprosessen, vil dere være anonymiserte for denne personen. Det vil ikke være mulig å identifisere dere i resultatene av studien når disse publiseres. Masterstudenten har taushetsplikt. Opplysningene og lydopptaket vil bli slettet og makulert senest innen utgangen av 2010.

### **Frivillig deltakelse**

Det er frivillig å delta i studien. Du kan når som helst, og uten å oppgi noen grunn, trekke ditt samtykke til å delta i studien. Dersom du ønsker å delta i prosjektet, så ber jeg om at du underskriver denne samtykke erklæringen så fort som mulig og returnerer den i vedlagte frankerte konvolutt. Har du/dere spørsmål til studien, kontakt gjerne Karen Kleivene på tlf. 97184043. Dersom du/dere senere ønsker å trekke deg/dere fra studien, meld ifra til Karen Kleivene.

### **Kontakt informasjon, masterstudenten og prosjektleder**

Karen Kleivene  
Klingremoveien 118  
4877 Grimstad  
[Karann4@hotmail.com](mailto:Karann4@hotmail.com)  
Mob. 97184043

Veileder Bjørg Fallang  
Avd. Helsefag, Høgskolen i Oslo  
[Bjorg.Fallang@hf.hio.no](mailto:Bjorg.Fallang@hf.hio.no)

## Samtykke til deltakelse i studien:

**”Smerte hos barn med multifunksjonshemminger og hvordan den påvirker familien.”**

Jeg samtykker i at opplysninger om meg kan samles inn fra intervju og kartleggingskjema utfylt av meg, og at de kan oppbevares under prosjektiden, innlåst i et skap hvor kun prosjektleder har tilgang.

Jeg forstår at deltakelse i prosjektet er frivillig, og at jeg når som helst kan trekke min deltakelse og be om å få slettet de opplysninger som er registrert om meg.

Jeg er villig til å delta i studien.

---

(Signert av prosjektdeltaker) (relasjon til barnet) (dato) (tlf)

Jeg er villig til å delta i studien.

---

(Signert av prosjektdeltaker) (relasjon til barnet) (dato) (tlf)

Jeg bekrefter å ha gitt informasjon om studien

---

(Signert, rolle i studien) (dato) (tlf)

**Demographic information for the Master Project:**

**"Pain in non-verbal children with severe multiple disabilities."**

The child's age:

The child's gender:

The child's diagnosis:

Number of siblings:

The child lives:                      at home                      in special housing

Parents live:                      together                      separated

Day program:

Respite:                      Yes    No                      How much:

Taking medicine for pain:    Yes    No                      Effect:            no    some    good

Other pain remedies: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Maternal age:                      Mother's education:                      Work / hours per week:

Father's Age:                      Father's education:                      Work / hours per week:

## Demografisk informasjon til prosjektet:

### “Smerte hos barn med multifunksjonshemninger og hvordan den påvirker familien.”

Barnets alder:

Barnets kjønn:

Barnets diagnose:

Antall søsken:

Barnet bor:                    hjemme            i spesial bolig

Foreldre bor:                sammen            adskilt

Dagtilbud:

Avlastning:                Ja                Nei                Hvor mye:

Tar medisiner for smerte:    Ja                Nei                Effekt: ingen            noe    god

Andre smertetiltak: \_\_\_\_\_  
\_\_\_\_\_

Mors alder:                Mors utdanning:                    Arbeid/timer per uke:

Fars alder:                Fars utdanning:                    Arbeid/timer per uke:

## **Interview Guide for the Master Thesis:**

### **"Pain in non-verbal children with severe multiple disabilities."**

**Theme: Pain in non-verbal children with severe multiple disabilities and how it affects activities of daily living in the family, from parents' perspective.**

#### **Research questions:**

1. How do parents **perceive and communicate** about pain in their child with severe multiple disabilities?
2. How does pain **affect activities of daily living** in the family?

*Suggestions for some questions to ask informants for discussion and descriptions of their experiences with pain and pains affect on activities of daily living.*

- 1. How do parents perceive and communicate about pain in their child with severe multiple disabilities?**

Can you tell me how you know that your child has pain?

What causes pain in your child?

What types of pain does your child experience?

How does your child act when he/she has pain?

How does your child express pain?

Does your child have different expressions for pain, and do they vary?

How do parents decipher expressions of pain from other emotional expressions?

How do you locate where your child has pain and how much pain he/she has?

When did you start thinking that your child's behavior depicted pain?

How have your child's expressions of pain changed over the years?

Have you received guidance regarding interpreting behavioral expressions?

Did you feel the NCCPC-R was helpful? Did you recognize behaviors in your child? Which behaviors did you recognize? Would you recommend others to use NCCPC-R? Who would you recommend it to?

**2. How does pain in your child affect activities of daily living in everyday family life?**

Can you tell me about everyday activities in a typical 24-hour period?

Can you tell me about everyday situations in the family which are particularly painful? (washing/grooming, dressing, feeding, digestion, bowel movement, transitions, mobility, sleep, etc.). How often do these occur? How long has this occurred?

When your child has pain, how does it affect your child and activities of daily living in the family?

What do you do to help your child when he/ she has pain?

How well does your child sleep?

If your child has trouble sleeping, can you describe a typical night, and what you think the reason is for sleep difficulties?

What helps your child fall asleep or go back to sleep once he/she awakes?

## **”Smerte hos barn med alvorlige multifunksjonshemninger og hvordan det påvirker dagliglivets aktiviteter i familien.”**

### **Forskningsspørsmål:**

- 1) Hvordan oppdager og kommuniserer foreldre om smerte hos sitt barn med alvorlige multifunksjonshemninger?
- 2) Hvordan opplever foreldrene at smerte hos barnet påvirker dagliglivets aktiviteter i familien?

### **Intervju guide:**

- 1) Hvordan opplever og kommuniserer foreldre om smerte hos sitt barn med alvorlige multifunksjonshemninger?*

Kan du fortelle meg hvordan du ”vet” at ditt barn har smerte?

Hva er det som gir ditt barn smerte, hva forårsaker smerte hos ditt barn?

Hvilke typer smerte kan ditt barn oppleve?

Når ditt barn har smerte, hvordan oppfører han/henne seg?

Hvordan kommuniserer ditt barn smerte?

Har ditt barn forskjellige uttrykk for smerte og kan de variere?

Hvordan skiller foreldrene mellom uttrykk for smerte og andre emosjonelle uttrykk?

Hvordan lokalisere foreldrene hvor barnet har vondt og hvor mye smerte barnet opplever?

Når begynte foreldrene å forstå/tolke at barnets adferd var uttrykk for smerte?

Har barnets uttrykk for smerte forandret over tid? Hvordan har de forandret seg?

Har du fått veiledning i tolkning av barnets signaler/uttrykk for smerte?



Du/Dere har sett på eller fylt ut NCCPC-R i forkant av intervjuet. Kjente du/dere igjen uttrykk for smerte hos ditt barn? Hvilke smerteadferd var mest representativ hos ditt barn? Ville du ha anbefalt andre å bruke NCCPC-R? Hvem ville det være aktuelt for?

2) *Hvordan opplever foreldrene at smerte hos barnet påvirker dagliglivets aktiviteter i familien?*

Kan du fortelle meg om en typisk hverdag (24t) i familien, med fokus på daglig aktiviteter/gjøremål/ADL?

Kan du fortelle meg om hverdagslig aktiviteter i familien som virker spesielt smertefullt/smertepreget? (f. eks. stell, av/påkledning, spising/mating, fordøyelse, avføring, forflytning, mobilitet, søvn, osv.)

Hvor ofte opplevs smerte eller virker barnet smertepåvirket i disse situasjoner?

Hvor lenge har dette pågått?

Når ditt barn har smerte/virker smertepåvirket, hvordan påvirker dette dagligdagsaktiviteter i familien/ADL?

Hvordan hjelper du barnet når han/henne har vondt?

Hvor godt sover barnet ditt?

Hvis ditt barn har vansker knyttet til søvn, kan du beskrive en typisk natt?

Hvorfor tror du ditt barn har søvnvansker? Hva er grunnen til søvnvansker?

Hva hjelper ditt barn å få sove eller sovne igjen når han/hun har våknet?