Investigation of Parental/Caregiver Concerns of Children with Spasticity

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INVESTIGATION OF PARENTAL/CAREGIVER CONCERNS OF CHILDREN WITH SPASTICITY

by

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A Thesis
Submitted to the
Faculty of The Graduate College
In partial fulfillment of the
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2003
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Finally, I thank my Lord and Savior Jesus Christ who plainly wrote the vision.

Lynda Johnson-Cross, M.S.
INVESTIGATIONS OF PARENTAL/CAREGIVER CONCERNS OF CHILDREN WITH SPASTICITY

Lynda Johnson-Cross, M.S.
Western Michigan University, 2003

Although there is capacious documentation on the concerns associated with parenting/care giving the disabled child, the concerns of parents/caregiver of children with the specific condition of spasticity is lacking. Therefore, the purpose of this study was to begin to determine the concerns of parents/caregivers of children with spasticity as they specifically relate to care giving. An extensive qualitative based survey interview was utilized to gather information from three informants. Analysis revealed clusters of concerns in the Nature of Caregiving, Spasticity Encounters, and Parental/Caregiver Comments.
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CHAPTER I
INTRODUCTION

Healthcare has seen the recent emergence of the specialized treatment of spasticity with the utilization of a multidisciplinary team approach. The ultimate objective for developing a team approach is to (a) improve function, (b) prevent deformity, (c) decrease pain, and (d) facilitate care (Albright, 1996; Campbell, Almeida, Penn, & Corcos, 1995).

The team may consist of a neurologist, physiatrist, orthopedist, neurosurgeon, nurse and rehabilitation therapist. The role of the therapist is to obtain spasticity specific data that is integrated through the set phases of treatment. Quantifying the degree and distribution of the spasticity and determining the extent to which the presence of tone interferes with care giving are crucial markers that are gathered by the rehabilitation therapist (Berry, 1998).

The parents/caregiver’s perspective is also an important part of the spasticity team treatment. Although parental/caregiver concerns as they relate to spasticity and caregiving can in fact become the driving objective, the literature is lacking in clear definition as to what specifically is of concern to parents (Berry, 1995). It is the aim of this study to begin to uncover the concerns of parents/caregivers of children with spasticity specific to care giving activity.
CHAPTER II

LITERATURE REVIEW

Parental/Caregiver Concerns

The concerns of parents/caregivers of children with disabilities can be chronicled along a unique course as compared to parents/caregivers of non-disabled children:

Parents of children have functioned in a doable bind. They, like all parents, are fully implicated in the behavioral and genetic actualization of their children. The parents of the child with disabilities must deal with the same feelings of guilt, failure, self-doubt, resentment and anger, as parents of “normal” children, while simultaneously coping with the excessive parenting demands imposed on them by their child who has special need. A child with disabilities frequently needs more time, energy, attention, patience, and money, than the normal child and frequently returns less success, achievement, parent pride-inducing behavior, privacy, feeling of security and well being (Paul, 1981, p.5).

Review of the literature suggests that the parental/caregivers concerns of children with disabilities are different from the concerns of parents/caregivers of non-disabled children. The different perspective is noted in issues both concerning their children and themselves. The review of these altered concerns will therefore consist of the examination of the emotional, social, service, child characteristic and care giving concerns categories.

Emotional Concerns

Stress

The existence of stress is directly related to the presence of the child with disabilities (Kazak & Marvin, 1984; Kazak, 1987; Dyson, 1991). Early discussions of increased stress in families with disabled children were explored by Dyson (1991). Dyson took care to increase the size of the study as compared to previous studies (110 families) and to utilize a compatible comparison group. Of additionally significance, Dyson controlled the participants for social economic status with the utilization of middle class families.
only. The inclusion of this subject criterion added fortitude for ruling out confounding results related to mixed social economic statuses.

The results were reported in terms of family functioning, parental stress, and predictors of family stress. Parents of disabled children scored significantly higher in the stress contexts than parents of children without disabilities regardless of socioeconomic status.

The specific sources of the stress can span the array through the life of a family (Hanson & Frances, 1990). A capsulation of the sources of stress is provided in McCubbin’s (1989) work on the comparison of stresses in the single versus two parent families of disabled children. She explains:

Altered family relationships, modification in family activities, burden of increased care, need for compliance with time consuming treatment regimens, financial strains, special housing and equipment needs, possible social isolation, grieving reactions and worry about the child’s prognosis and future and potential can contribute to the stress experienced by these families (p. 101).

Mothers frequently report the events extending from birth to early childhood as the “most stressful” (Kazak & Marvin, 1984; Pasmore, Pletcher, Wsitch, & Cress, 1989). Specifically, the circumstances prompting these reports include the initial discovery of abnormality, the diagnosis process and the experiences of the general grieving process.

Pasmore et al. (1989) video recorded the responses of parents with children with disabilities during initial discovery period. In Pasmore’s recordings, parents agree that the first few months are often the most difficult. Apparently, this period becomes the “epoch” as it is embellished by the overwhelming anxieties associated with the sense of something being wrong with the child. Accentuating the frustration is the reality that the parent’s suspicions were not customarily collaborated by the physicians. Indeed, Pasmore’s group collectively reports feeling pervasively confused when their suspicions of abnormality were met with inconsequential physician recommendations (Pasmore et al., 1989).

Subsequent to parental suspicion of the child’s condition is the diagnostic process, which often creates an emotional upheaval. Parents report that the diagnostic process does not necessarily proceed along a predictable path. The specific element of uncertainty associated with the “waiting period” is identified as an agent of stress (Pasmore, Pletcher, Wsitch, & Cress, 1989).
When examining the coping behavior of 28 parents of cerebral palsy children, Hirose & Ueda (1990), confirmed that early childhood diagnosis being a difficult time for parents, and again, especially for the mothers. Two items of significance relative to this early period were established. First, the parent’s sense of something being wrong with the child is often more than intuition and is often eventually substantiated. In fact, it is the diagnosis of cerebral palsy that is more often later determined (either athetoid or spastic type). Secondly, Hirose and Ueda’s (1990) study demonstrated that diagnosis could be timely. When parents felt suspicious of developmental disabilities as early as in the first month, they were not told of the cerebral palsy diagnosis for up to three years. Hirose and Ueda’s (1990) population reported that they visited from two to eight (X=4.1) health care facilities or social welfare agencies in search of consultation during such a period.

It has been demonstrated that when examining the emotional response to the presence of a disabled child in the family, stress is the dominant theme. Other themes emerge as well including pessimism, depression, anger, grief/guilt, the senses of uncertainty, differences in affective involvement and gender perception differences.
Pessimism

Pessimism has been identified as an emotion that emerges later in families of disabled children. It appears in parents of disabled children in a defining state during the child’s adolescence period (Dyson, 1997; Magill-Evans, Darrah, Pain, Adkins, & Kratochvil, 2001; Rousey, Best, & Blacher, 1992). Defined as “worries regarding the future,” pessimism scores were significantly different between mothers and fathers of the disabled, with mothers scoring higher on this factor (Rousey et al., 1992).

Rousey et al. (1992) explored the comparison of stress and coping strategies in mothers and fathers of disabled children, and included a sub-scale of pessimism sensitivity. This sub-scale uncovered significant mother father differences. Beyond dramatizing the differences between parental reactions in the area of pessimism, Rousey et al. also portrayed the correlation between pessimism and child characteristics. The parents of the more physically disabled children scored higher on the pessimism scale.

One of the most significant findings in Magill-Evan’s et al. (2001) study was that mother’s of severely involved cerebral palsy adolescents and young adults scored lower on measures of future expectations for their children. It has been suggested that the pessimism scores among parents/caregivers of disabled children may in fact, be a correlate to the parent’s willingness to except the realities of the child’s impairments (Rousey et al.1992).

Anger

Anger is also reported as an emotional response of families with disabled children. Baird, McConachie and Scrutton (2000) relate this component to the diagnostic process. The most frequently cited concerns were related to disclosure including the lengthiness in the diagnostic process, uncertainty of the child’s condition and professional mannerism. Kazak and Marwin (1984) acknowledge anger toward professionals as a possible normal response. They suggest that professionals should encourage more informal (rather than formal medical) social networks in order to support family functioning.

Depression

In addition to stress and anger, there appears to be a direct correlation between parental depression and the nature in which the diagnosis was disclosed. It appears that parents report more dissatisfaction with
the disclosing process when the child's condition is more severe. Specific identified conditions are low birth weight, pre-maturity, and the eventual development of severe physical disabilities (Baird et al., 2000).

The report of depression in parents of disabled children is also frequently correlated to care giving. Rousey’s et al. (1992) study separately explored the perceptions of mothers and fathers of children with severe disabilities. Through factor analysis, a category did emerge for both parents and it was linked to depression associated to care giving. Depression’s relationship to care giving appears to be related to the time and energy factors (Kazak & Marvin, 1984; McLinden, 1990). Depression as it relates to competent care giving is more frequently related to mothers than fathers (Paul, 1981).

Satisfaction

Life satisfaction/dissatisfaction rating scales have provided additional insight into the emotional status of parents and/or care givers of disabled children. For example, Magill-Evans et al. (2001) sought to compare families with cerebral palsy adolescents and young adults to families with physically intact adolescents and young adults. The objective was to investigate similarities and differences in life expectations of parents. Families were secondarily divided by ratings of severity of cerebral palsy. The more involved group of persons with cerebral palsy (cp) was labeled cp-2. The lesser-involved group was labeled cp-1. The study’s timeframe of entering and leaving adolescence was unique in its core question. Of the four scales utilized to convey the outcomes, the Life Satisfaction Scale proved significant for fathers and siblings. Fathers of the cp-2 group scored significantly lower on life satisfaction than cp-1 or the control group for both adolescents and young adults. Siblings scored lower in the cp-2 groups only and for the adolescents alone.

Grief/Guilt

The grieving process is reported to be pronounced in the early childhood period for parents and/or care givers. It can often be characterized as an emotional ride that is intensified by the stress of fluctuating feelings (periods of guilt and denial) (Baird et al., 2000; Tackett & Kerr, 1990; Pasmore et al. 1989). Parents of disabled children report that the mere day-to-day experience of emotional vacillation is stressful yet a necessary component to the grieving process. When Pasmore (1989) addressed this issue, he noted
that guilt rumination is a constant stressor. Vacillating feelings of self-indictment were expressed in the question: “what did I do during my pregnancy.” Others reported the revolving sense of having a “broken doll” as being guilt producing. The group concluded that the need to move on from guilt and grief on to reality management was difficult because of the ever-present sense of uncertainty.

Uncertainty

Uncertainty is identified across the span of parental emotional concerns. When comparing the perceived stressors of disabled children and their mothers, Tackett and Kerr (1990) recorded “newness and uncertainties” as one of the top three stressors of mothers of early school age children. Many parents describe an endless sense of uncertainty that is indeed a contributor to enduring stress. As one Pasmore et al. (1989) informant states, “Always being ready for the unexpected is stressful.” As the child develops, the families begin to increasingly experience the stress of coping with the long-term uncertainty of the child’s future functioning (Kazak & Marvin, 1984).

While exploring the state of the mother’s well being, Harris and McHale (1989) reported that eighty-three percent of those surveyed recounted anxiety within the past year over the present and future health and well being of their child and that these worries had been problematic. Mothers emphasized that it was the ambiguity associated with the child’s prognosis or the uncertainty of the family’s ability to meet the child’s needs that contributed to incessant emotional disruption.

Affective Involvement

Using the Affective Involvement Scale, Magill-Evans et al. (2001) measured the extent to which family members are interested in each other’s activities and concerns. Their study revealed that fathers of adolescents scored significantly lower on this measure. Interestingly, the fathers of the cerebral palsy group with less physical involvement had the least optimal score for affective involvement.

Gender Differences

An alternative view of the emotional response of parents/caregivers to the presence of a disabled child can be extracted from the examination of gender differences. In doing so, a consistent pattern of differences between genders emerges across studies. In terms of the emotional response, mothers experience
more stress, depression, anger and guilt than fathers (Bailey, Blasco, & Simeonsson, 1992; Kazak & Marvin, 1984; McLinden, 1990; Timko, Stovel, & Moos, 1992). One differentiating factor appears to be related to care giving. The degree to which care giving is perceived to be difficult, time consuming, demanding, and role restricting is proportionate to the differences in perceived stress between the genders (Kazak & Marvin, 1984; Roach, Orsmond, & Barratt 1999; Timko, Stovel, & Moos, 1992; Willoughby & Glidden, 1995). It has also been demonstrated that the mother’s emotional response to the demands of the disabled child is linked to marital satisfaction and the perceived sense of spousal support (Gowen, Johnson-Martin, Goldman & Appelbaum, 1989; Rousey, 1992; Willoughby & Glidden, 1995).

When Hirose (1990) examined the long term coping patterns of parents of children with cerebral palsy, he discovered a dichotomous emotional response between fathers and mothers in the first three years of the child’s life. The mother’s reactions to the diagnosis were generally assessed as more emotional (as compared to the father’s) and categorized into three types. The first was “the pessimistic.” Mother’s of this group said such things as, “I couldn't think at times,” and, “I wanted to commit suicide with my child and I couldn't do anything but weep.” The second type was “the optimistic,” reflected in statements such as, “I suppose he will grow up with little or no disability with treatment.” The last category was the “objective type.” Their responses minimized the cerebral damage as noted by statements such as, “I intend to raise the child as the same as a normal child because there is no damage to intelligence.” The variability between the fathers and mothers was found to be significant. Forty-two (42) percent of mothers expressed a pessimistic view with 46% having an optimistic view while 10% of fathers expressed optimism. Ten percent of mothers were noted to have objective views about their children’s disability compared to 83% of fathers.

Social Concerns

When reviewing the literature pertaining to the social domain, themes that emerge include social accessibility, communication, altered social networking patterns, and relationship development.

Child’s Social Accessibility
Parents have reported concerns associated with social mechanisms. Tackett (1990) explored the similarities and differences in concerns between mother and child (school aged children). The results clearly clustered in the social scales versus the physical. Although it is a circuitous line between concerns from the physical to social domains, teasing and acceptance at school were highly ranked by both mother and child as being of primal concern (as opposed to situations related to frank physical limitations). The results reverberate the original assumption of the study: that the major problems perceived by parents/caregivers of the disabled school age child, evolve around the social rather than physical.

A parent’s and/or a care giver’s social concerns coming second to the child’s physical disability were substantiated by Lepage, Noreau, Barnard and Fougéyrollas (1998). Here, a profile of disabled situations in children with cerebral palsy was compared to disability type and severity. The study concluded that children with cerebral palsy are poorly integrated socially in the recreation and community “habits.” In addition, it was demonstrated that severity and type did relate directly to the degree of social limitation (quadriplegics more restricted that hemiplegics or diplegics). Of note, it was also displayed that non-physical disabilities (deafness, speech impairments) were also limiting in social accessibility.

Communication Social Concerns

Communicating the disabled child’s social status is ranked as one of the initial and most difficult social concerns (Kazak, 1994). Following the revelation of the child’s condition, parents are immediately propelled into the necessity of sharing the condition of the child with others. This often occurs before the parents have effectively coped with their own feelings and perceptions about the disability. “Explaining to others” has specifically been attributed to reports of parental stress. The collection of the “others” group has been identified as spouses, parents, in-laws, friends, neighbors and strangers (Bailey, Blasco, & Simeonsson, 1992).
Social Networks Concerns

Kazak and Marvin (1984) described the social network concept. Their study explored the differences, difficulties, and adaptation in families with spinal bifida children when compared to a matched control group and described the status of the social factor in these families.

First, social network size refers to the number of persons identified as providing social support. It has been traditionally accepted that the larger the network size, the greater the likelihood of successful coping and adaptation. Secondary analysis however suggested that size was not correlated to adaptation, and it was speculated that size does not reflect the quality of the network. On the other hand, the study did show a network size discrepancy as the parents of children with disabilities did have significantly smaller network sizes.

The second idea of this study is social network density. Density pertains to the extent to which members of an individual’s social network know each other, independent of the focal person. To clarify, high-density network members know each other through inter-related links. Low-density network members tend to know only the focal person. Parents of the spina bifida group had higher density group scores as compared to the control group. Kazak and Marvin’s (1984) explanation for the results is that development of friendships is based largely on sharing common interest and activities. The unique nature of families with disabled children appears to significantly reduce opportunities for generating interest to which outside relationships are based.

The third construct of the study, the social network boundary, is similar in character to network density. Social network boundary is the measure to which two individuals have overlap in shared network members. In the case of this study, mothers and fathers had large network boundaries. In other words, mothers and fathers of the spina bifida group had a greater tendency to share the same social contacts when compared with their counterparts. Ramifications between social network density and boundary were found to be similar.

The social network higher density and larger boundary size of the spina bifida group was linked to parental concerns in a surprising orientation. Although social networking may foster a sense of cohesiveness, it was evidenced that the nature of this group’s social network may actually self germinate
conditions for increased stress. It was determined that higher density social networks were associated with higher levels of stress. Kazak and Marvin (1984) postulated that high-density social networks may in fact stifle independence and secondarily reduced opportunities for diverse adaptations.

Service Concerns

Social, medical and educational services are suggested as areas of concern for parents and/or care givers of disabled children (McCraven, 1976). The service concern is a longstanding one as accessing a single and/or a combination of services is likely to be a lifelong quest. Perceived concerns of availability, information, and professional integrity are interpretations of service delivery, which is also configured differently among gender, racial, and community lines.

Availability of Service

A double bind has also been postulated for families with child with disabilities when attempting to access services. It appears that service does not preclude service acquisition. While investigating the service needs of families of child with disabilities Sloper and Turner (1992) determined that the families with the highest levels of service needs were in fact more likely to have unmet service needs. Moreover, this study was able to link the presence of unmet service needs with the experience of high levels of strain and stress.

The concerns of service accessibility are a cause of great frustration (Kazak & Marvin 1984; Matteson, 2001; McCraven, Phenicie, Graz, & Kyle 1976; Michigan Public Health Institute, 1996; Pasmore, Pletcher, Wsitich, & Cress, 1989; Paul, 1981; Atwell, Seelig, & Joliffe, 1974). Self-navigation by one parent in Pasmore’s group was likened to “a maze walk” families report this frustration across the social economic stratum. On one hand, parents/caregivers report that they are aware of the need for services but unaware of the acquisition course. On the other hand, families report knowledge of the acquisition process even though services remain unavailable to them (age, finances, travel distances).

Mattsson (2001) suggests that there is a degree of parental/care giver stress that is contributed by the decrease in the quantity of rehabilitative services for the aging child. As the child ages typically there is reciprocal decrease in rehabilitative directed services. Buttos, Feliciangeli, Sciuto, Gericke, and Vianello (2001) substantiated this parental concern as a realistic event. This long-term follow up study examined the
status of cerebral palsy children to adulthood. Here it is determined that services were significantly reduced with age and more importantly, that functional physical status also deteriorated significantly.

Information from Services

Once the family has accessed the service institution, securing needed information is reported as a primary goal. Curiously, however, obtaining the information has also been reported a source of stress and a concern. In a review of the service needs of these families, Sloper and Turner (1992) postulated that under certain circumstances services might exacerbate rather than moderate stress particularly through avenues of the worry and difficulties of obtaining help and information.

Gender perspectives appear in agreement with the service concern category. When examining the expressed needs of mothers and fathers in terms of similarities and differences Bailey’s et al. (1992) design yielded six categories from the factor analysis. Of the six, half were identical in nature for both mothers and fathers. Within that cluster, service needs were in common. The structure of service need was that of more information as it related to the management of the disabled child (Bailey, Blasco, & Simeonsson; Sloper & Turner, 1992).

Service Provider Professional Integrity

A third less prominent yet significant service category is that of professional mannerisms which include timeliness and communication. One of the major problems recorded in surveying recipients of Michigan’s Title V (1996) is the wait time for appointments with primary and specialist physicians. In addition, the specialist not being available after hours was also delineated as a stressing concern.

Communication technique is the second professional mannerism identified as a stressing concern during both taped sessions (Pasmore et al., 1989; Atwell, Seelig, & Joliffe, 1974). Embodied within this sentiment is the discomfort of others not understanding what is being said. It is agreed that this becomes most disruptive in relation to serious medical procedures or conditions. Furthermore, these parents also tabulated rudeness in communication as a recurring anticipated event during medical visits. In their own defense, parents retort, “we are not dumb… we want someone to listen to our concerns.”

Educational Services
When the disabled child enters school, parental concerns are reconfigured. The Pasmore group (1989) was rather sonorous in their echo of educational concerns. These parents exclaimed the need for information in how to integrate the educational goals into the home. Home management for specific difficulties and behavior was a recurring request from this group. Future educational and community plans along with listings as to where to find additional help were all reported informational concerns. In terms of family focus and support, this group indicated the need for educational goals to be family specific versus child specific. Lastly, support and recognition for what the families have accomplished and have demonstrated competence in, were repeated expressed desires of the group.

Community and Racial Differential Perspectives of Services

In 1976, an urban Los Angeles community mental health agency launched a project to examine the perceived nature of health services in the urban community. Essentially the attempt was to identify the level of awareness in a low-income urban community as it related to disabling conditions in children. The results were contrary to traditional held notions of the time.

McCraven (1976) argues that traditionally, the targeted population has been collectively identified as ignorant to preceptors of disabling conditions. The data of the study indicated an alternative view. First, it was determined that the populace of the urban community is knowledgeable about disabling condition in children. For example, respondents were able to identify causal relationships to disabling conditions and they were able to identify developmental milestones. Furthermore, community residents of the study were aware of the significance of early identification with 97% having correct answers on this question. Of most significance to this study was the inability of respondents to name resource programs and resource agencies available to serve the child with disabilities. The study suggests that addressing the lack of resource awareness in urban communities should be an integral factor of health care services to these families.

When examining recipient satisfaction of state funded insurance for children in Michigan, known as the Children's Special Health Care (C.S.H.C.), the Michigan Public Health Institute (1996) discovered polarities along racial lines in clusters of insurance, satisfaction, general problems, accessibility and provider difficulties. The Native Americans of the study were most likely to have C.S.H.C. care alone. Native Americans and African Americans most frequently had C.S.H.C. and Medicaid combined. African
Americans reported the least amount of satisfaction in categories of access and relationship with the primary provider and the specialist. Native Americans reported the least satisfaction with C.S.H.C. Whites and Asians indicated problems with coverage for needed services and equipment. Native Americans reported problems with the amount of paper work associated with insurance coverage and African American respondents found the system problematic in the location of providers who accept Medicaid.

**Child Characteristic Concerns**

The literature is lacking in the in depth exploration of the relationship between the child’s characteristic and parental/caregiver concerns. Typically, studies examine parental/care giver concerns by diagnostic type of the child. Careful analysis however reveals that (Dyson 1991; Hanson & Frances, 1990; Rousey et al., 1999) a positive relationship exists between diagnostic attributes and characteristics of the parental/care giver concerns.

**Physical Attributes**

Physical and multiple disabilities are contributory to greater degrees of parental concern and stress as compared to single disabilities. In Hanson and Frances’ 1990 study, mother-child pairs of Down’s syndrome hearing and neurological impaired were evaluated across a longitudinal study. The neurologically impaired included spina bifida and cerebral palsy. Thirty-five mothers and their children were observed and interviewed three times over the course of the study. Two questionnaires and a stress index were the methodological instruments The study sought to explore the relationship of the child’s type of disability and maternal stress, the nature of change in any such relationship over time and the ramification between stress and satisfaction with social support. Using the Parental Stress Scale cross-categorical analysis was performed on two main subscales: the child’s domain and the parent’s domain. Areas such as the child’s adaptability, demandingness and mood were correlated with items of depression attachment and sense of competence from the parent’s domain.

Parents of the neurological impaired scored higher on all factors. In other words, mothers of neurological involved children reported the most stress. Hanson and Frances (1990) propose that the
phenomenon may be reflective of the complexity of complications associated with the physically impaired and/or the multiply physically impaired.

Even though specific features of the child’s disability has received little attention there is evidence that supports that the examination may be essential in unraveling the generalized data of parenting/care giving the disabled child. Tew and Laurence (1975) demonstrated that stress levels within the same diagnosis are different based on attributes. This study related significantly higher levels of inventoried stress in mothers of spina bifida based on continence/incontinence. Mothers of children who were incontinent rated higher in stress indicators than mothers of spina bifida children who were usually continent. Again, it should be here underscored that when looking at specific characteristic within a group (versus examining diagnostic groups) increased levels of maternal stresses were found. Similar subject classifications were also utilized when looking at a group diagnosis of prematurely. Neonates were specifically grouped for study by, “more irritable” and “less socially responsive” (Beckman, 1983).

When Gowen 1989 et al. studied the relationship of maternal depression and feelings of competence with measures of child characteristics. Additional support for this relationship was obtained. The results were dramatized through the synopsis of one of the mother who added real life dimension to the child-characteristic domain. She related the demise of never knowing when a seizure could “wipe out the child’s progress.”

Care giving Concerns

The caregiving factor is identified as a primary concern of parents/caregivers of children with disabilities. This concern essentially is associated with the degree of time/energy, the difficulty and unusual nature of the tasks, and the division of caregiving task burdens (Curran, Sharples, White, & Knapp, 2001; Paul, 1981).

Gender Differences

Sampling the status of care giving tends to be reported from the mother’s perspective. Clearly, women provide the majority of care. On the other hand, the data remains unstable and/or inconclusive in regards to the degree to which fathers share with care giving. Subsequently, when studying concerns related
to care giving, it is the mother’s well being that remains the primary correlate with stress and concern (Dyson, 1991; Kazak, 1987; Barakat & Linney, 1992; Willoughby & Glidden, 1995; Timko et al., 1992; Harris & McHale, 1989).

Mothers invest considerably more time and energy in the parent-child relationship (McHale, 1989; McCubbin, 1989). There is a high cost to the mothers as a result (Beckman, 1983; Erickson & Upshur, 1989; Kazak & Marvin, 1984; Gowen et al., 1989; Harris & McHale, 1989). Highly invested care giving mothers are reportedly more susceptible to physical and psychological pathologies. Elucidation of this relationship is seen in the Roach et al. (1999) study. This study pursued exploration of the perceived stress differences between mothers and fathers as they relate to childcare involvement. The results indicate gender differences in child-related stress, parent related stress, depression, and role restriction and health difficulties. These differences were rated higher with mothers who assumed more responsibility for the childcare versus a more shared scenario.

Of note, the affective variable emerged in this study of care giving/gender difference. Roach et al. (1999) was able to demonstrate a direct positive attachment/childcare relationship. Fathers who were responsible for more childcare tasks reported less difficulty with attachment.

Curiously, childcare division and marital satisfaction has been reported in tandem. Although the degree to which fathers are sharing in the burden of care giving has not delivered stable data, it is suggested as linked to marital satisfaction. When specifically evaluating the relationship of childcare division and marital satisfaction in families with disabled children, Willoughby and Glidden (1995) demonstrated that the father’s participation did in fact relate to greater marital satisfaction.

An intriguing relationship emerged in appraisal of marital satisfaction and physical characteristics and of degree of impairment. Mothers’ scores on marital satisfaction were in direct positive correspondence to the child’s incapacitation (Rousey et al., 1992). In other words, the more profound the disability and subsequent incapacitation, the greater the marital adjustment was for the mother. The suggested postulate was that the incapacitation of the child necessitated the father’s involvement. An extension of this concept is also supported in Willoughby and Glidden’s study (1995) where a direct relationship was conveyed between marital satisfaction and division of the care giving tasks between mothers and fathers.

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Time, Difficulty, Unusual Nature

The time, difficulty, and unusual nature factors are picturesque to the recursive archetypes of the caregiver concern domain. These variables were dramatized in Erickson and Upshur’s 1989 study of the caregiving burden and social support. Erickson and Upshur (1989) selected four groups of mothers of infants. Three groups comprised of mothers of Down’s syndrome, motor impairment and developmental delays were compared to a match control group. The variables not only generated significant differences between the disabled and non-disabled groups but disability specific differences also emerged. Mothers of the Down’s syndrome group reported significantly more time required for care-taking. In addition, mothers of this group also reported more difficulty in feeding, bathing and dressing as compared to their counterparts.

Mothers of infants with motor impairments did not differ significantly to the comparison group in terms of difficulty however a significant difference did emerge in terms of time.

Finally, mothers of infants with developmental delays comprised the group with significant ratings of difficulty for feeding, bathing, and dressing when compared to the control group. The motor impairment group and the developmental delays group were congruent in care-taking time cost.

A critical element in caregiving is the concern of childcare resources. Mothers frequently complain of few opportunities to escape from the intensity of childcare. The lack of respite that mothers receive from the day-to-day care of the child has been substantiated as a parental/caregiver concern (Gowen et al., 1989). Mothers of young children report that one of their greatest problems is that of finding child care (Gowen et al., 1989).

Unusual and Difficult Nature

The unusual and difficult nature of caregiving has been rated high on problematic task hierarchies. Beckman (1983), explored the association between unusual and difficult care giving for infants with disabilities and levels of parental stress. Of the care giving tasks, feeding is often the task that was identified with elevated levels of stress. The stress of feeding can be overwhelming. An intimate look at this task
reveals that it shares both factors identified as stressors in care giving. It is time consuming and it can be
difficult and unusual depending the features of the disability. In addition, when stress of caregiving is
correlated to feelings of incompetence, it was the task of feeding that was recurrently identified (Beckman,
1983; Dyson, 1991; Harris & McHale, 1989). Dyson goes on to suggest that because of the difficulty of
feeding and the psychological attachment of the mother, feeding is often delegated to less emotionally
involve family members (Dyson, 1991).

The degree of difficulty and unusual nature of in childcare tasks has been implied in direct
relationship to the degree of stress of mothers of the disabled. A suggested relationship is that mothers who
perform difficult and unusual care giving task are also the same mothers of seriously involved disabled
children. This may not be surprising given the critical nature of some procedures that these mothers
routinely perform (tube feedings, respiratory care, medication dispensing) (Gowen, et al., 1989).

Adaptation

When reviewing the response of parents/caregivers to having a disabled child, one should note that
the composite of sensations does have an interesting counterpart. It seems that frequently, over the course of
time, resilience potentials are often released within these families (Dyson, 1991; Hanson & Frances, 1990).
In other words, even in the presence of emotional strain, altered social relationships, service needs, child
characteristics, and care giving concerns increased, these families often find coping mechanisms.

Certain conditions appear to be more favorable for this adaptive response. Two parent families
appear to be more favorable. Single mother’s coping patterns were significantly lower in McCubbin’s 1989
study which specifically compared the functioning of single and two parent families of disabled children.
Previous internal coping strategies have also been identified as supportive. Social and service supports are
consistently reported as contributors of adaptation. The peculiar association with the support and adaptation
relationship is that those who report the most stress (parents/caregivers of the neurological and/or highly
involved) report the lease amount of support. Finally, the absence of contingent beliefs about the cause of
the disability is also encouraging to adaptation (Dyson, 1991; Hanson & Frances, 1990; McCubbin, 1989).

Significance
It has been demonstrated that parental/caregiver concerns of children with handicaps can span a
vase spectrum through the life of a family. Among the numerous concerns identified, caregiving is well
established. The literature is scant however, in establishing those concerns to distinct conditions. Significant
to this study is the absence of an established relationship between of the parental concern of care giving and
spasticity.

Spasticity is a characteristic in a number of handicapping conditions. It has been demonstrated that
the etiology of spasticity is the result of a central nervous system insult. Individual specialists focusing on
etiologic or pathologic sites have traditionally directed treatment of spasticity.

Recently health care has seen a shift from the treatment of spasticity to the utilization of the
specialized spasticity multidisciplinary teams. Parental/care giver concerns are utilized to determine the
treatment goals. Specifically, inquiry is made to measure how the presence of spasticity is portrayed in
caregiving concerns. Currently, there is little or no data to guide this spasticity specific inquiry.

Therefore, it is the aim of this study to begin to determine the concerns of parents/caregivers of
children with the specific condition of spasticity. Specifically, the relationship of spasticity and caregiving
will be explored.

For the purpose of this study spasticity is defined as a motor disorder characterized by velocity
dependent increases in tonic stretch reflexes with exaggerated tendon jerks, resulting from hyper-
excitability of the stretch reflex (Engsberg, Olree, Ross, & Park, 1996). The clinical presentation of
spasticity is marked by a physical status varying degrees of resistance to passive stretch, reduction in the
active range of motion and/or an increase in effort to activate the end range of motion. There is also an
overall loss of coordination and muscle strength (Katz, 1989; Young,Wiegner 1987 ) resulting from hyper-
excitability of the stretch reflex (Engsberg, Olree, Ross, & Park, 1996).

Management of spasticity is seen across modalities. Sound options include the rehabilitation,
surgery, injections oral medication and baclofen pump implantation. These options were often decided by
individual disciplines. The more recent option of the multidiscipline team is most relevant to this study
(Albright, 1996; Albright, Barron, Fasick, Polinko, & Janosky, 1993; Albright, Cervi, & Singletary, 1991;
CHAPTER III

METHODOLOGY

Research Design

The purpose of this study was to begin to uncover the concerns of parents/caregivers of children with spasticity. A semi-structured interview was used to glean this information. Subjects were asked to share information on care giving routines that included dressing, bathing, feeding, transfers and positioning. The subjects were also encouraged to identify and quantify the physical location of spasticity on their child and during caregiving routines. Finally, subjects were asked to share personal reflections.

Subjects

Three mothers of daughters with known spastic quadriplegia participated in semi-structured interviews. Interviews extended from one and one half two hours. The interviews took place in the homes of the participants.

The child of Case A was eighteen years old, Case B was five years old and Case C was sixteen years old. All three children had participated in spasticity management at some time. Case A was taking oral baclofen at the time of the interview. Case B had recently had a baclofen pump implantation and Case C recently had a baclofen pump discontinued.

Data Analysis

The interviews were audio taped and transcribed. Transcribed interviews were individually unitized yielding six original categories (Lincoln & Guba, 1985). Of the six original categories, three were maintained as themes. Although each category was reviewed separately, common themes did emerge between them.
CHAPTER IV

RESULTS

Nature of Procedures

Information in this theme clustered around the specifications of procedures, schedules, and sequences of dressing, bathing, feeding, transferring, and position. Multiplicity of steps, frequency/repetitiveness, and workload were the three categories that clustered in this theme.

Multiple steps

Items in this subcategory were inclusive of care giving tasks that required more than three steps to complete.

For all three cases, dressing was described most frequently in this category. Dressing was described with specific steps identified. Sequencing occurred unanimously from the waist down first. The diapers were first followed by pants, socks, and ankle braces (Case A only). Case A and B continued with the shoes before moving to the upper body while case C moved to the upper body after the pants. Braces were reported as a part of lower body dressing for case B only. Additional tasks were performed to preserve original steps and each clothing item represented specific objectives:

I'll put an extra liner in because as she gets older if she does use the bathroom, there is much more volume so a regular diaper is not going to necessarily hold all that volume and I don’t want her to have an accident at school and be embarrassed, so I’ll put an extra pad insert in there and I’ll put the diaper on her ... and if I know that we are going to be really messy or if there is something she is going to get (to eat) like if we are going to have a lot of bacon or sausage that is greasy, then I will put a bib that I have, that is like a big hair-cutting bib that works... really well and if not, then I’m going to put a regular T-shirt on her to where I can change the shirt, (again if necessary) I'm not going to go and put on extra pants or whatever because before she leaves, if it’s been a long time I can put her back up on the counter and just change her right quick without taking all that stuff back off. (Case B).
During bathing the multi-tasking occurred primarily during the set up and the drying off process. The set up unanimously was initiated with the water preparation, “I have a basin. I get the water ready and get everything set up right by the bed, all the toiletries and those kinds of things,” (Case A). The drying off process, in all three cases, includes multiple towels, transitions and positions.

Usually what happens I’ll line the potty chair with the towel and then I will lift her up and put her in the potty chair and so her back is already toweled and then I put the towel in front of her, then I put another towel on the counter, then I’ll wipe her off while she is in the chair because, I’ve washed her hair so I’m drying it off with another towel. Then I’ll wipe off the front of her and lift her arms up and wipe all under her arms, drying off her neck and everything, the back of her neck, drying off her chest. Then I’ll lift her and put her back on the counter on to the towel (Case B).

Left versus right side sequencing was specified in case A only. In terms of feeding, only the set up was reported by all of the mothers as requiring multiple steps. Cases A and B reported the addition of steps required for transferring and positioning after medical interventions. Case A recently had back surgery for scoliosis, which included the placement of rods. The recommended post-surgery precautions necessitated extra steps. “After I put her in her brace, I have to get her off the bed. I can’t lift her anymore just straight up like I used to, I have to sit her up on the edge of the bed, so I turn her sideways and have her bottom close to the edge so I can pull her up,” (Case A).

Case B recently had a baclofen pump implantation. The reduction in tone eliminated the weight bearing synergy that the child was using to assist with transfers. “… because before the pump she would be tight and everything would tense up and she would be like a board…you were just leaning a board up. But now everything is loose so it’s like a rag-doll,” (Case B).

**Frequency/Receptiveness**

Items in this category included tasks that occur two or more times a day or tasks that were intrinsically redundant.

Bathing is reported to occur from two to three times every day. Sponge bathing is identified in the morning and the evening on a daily basis for cases A and C. Case B has an additional bath (sponge) that
occurs immediately after school. Full bath or showers are reported from one time a week to nearly nightly. All three mothers report that there is a repetitive nature in associated to the actual washing process. “... you are forever rinsing off and wringing out, ... instead of being able to splash the water or hold the shower head and then just let it all rinse off”, (Case A). “Then I'm periodically dipping and re-socking the rag,” (Case B).

Only case A reported a repetitive nature in sequencing of the actual feeding process (Cases B and C were encouraged to feed themselves). The receptiveness is associated with the alternation between spooning and drinking.

Transferring and positioning tasks are rehearsed more frequently in this theme as compared to dressing bathing or feeding tasks. In fact, transferring and/or positioning were reported to occur before during and/or at the termination of all other care giving tasks. For example, when asked what was the first thing that is done for dressing, Case C replied, “Take her out of her chair, lay her on her bed (then)...remove her shoes...” Transferring and positioning tasks were related most frequently in conjunction with bathing. Note that during this discourse on bathing, Case C performs six transfers before the actual bathing process begins.

...I put her on her potty-chair and then we go and lock her wheels and put her up on the counter and get her undressed... put her back on the potty seat. Put her over the toilet and tell her if she has to go to the bathroom to go ahead and go... Get her back on the counter to wipe her... back in the potty-chair and ... and then put it back next to the tub, lock the wheels again, and then lift her from the chair on to the bath chair.

Workload

Items that surfaced in this category tended toward the identification of physical labor items.

Two mothers report that they are the sole caregivers. They report gaining assistance for specific occasions and tasks by family members. Two mothers report assistance on occasion from their spouses.

Workload issues were primarily linked to discussions of transfers and positioning. All three mothers describe the performance of a maximum assistance transfer where the child is cradled under the
legs and around the trunk. Case C maintained that the full extents of her “concerns” in care giving were interlaced with the physical cost of transferring and positioning. The frequency of transfers were reported to occur from four to the upwards of fifteen times in a day.

The performance total transfers with extensive workload demands were reported frequently. Case B and C carry their children upstairs for the upper level bathtubs. Case B relates that the bathroom counter top is her “adaptation” for height differentials during bath and toilet transfers... “you know, and I’m struggling on my end in the bathroom on the counter because as far as my back goes. Also, outings can include multiple transfers from difficult height discrepancies... The transfer from the wheelchair to the vehicle in Case A was mention as quite difficult...”

We put her in the wheelchair ... and wheel her around to my truck and then I lift her from the chair to the truck and then the truck back to the wheelchair. I lift her if we’re out going to the store or whatever. [If] I go in she goes in, so I take her wheelchair out and then go through that process again (Case A).

The mother to child size ratio was sited as workload contributor. “... I’m 125 and I think she is 97...” This ratio and the secondary workload cost were also sited by this mother as a primary reason for reducing the number of baths in the tub. Case B reported a belief that it was the small size of a school attendant that interfered with transferring efficiency for her daughter.

Selection

This is the area that surfaced data in regards to why certain care giving processes, adaptations; or equipment were preferred. The primary reasons given were ease of care, range of motion limitations, encouragement of independence and multiple uses of equipment.

Ease of care was the primary reason given for care giving processes development. More specifically, ease of care associated with limitation in the range of motion with the dressing and bathing process. Pullover shirts were avoided secondary to the limited range of motion in the shoulders and replaced by buttoned from or zipper upper body garments. Cases A and C report starting on the most
involved side first because more "slack" is required during dressing. In all three cases, the lower body was dressed first "because it is the 'most difficult'."

Limited range of motion in the lower extremities is identified as a contributor leading to the selection of the bathing/cleaning location. One mother reported that difficulty of flexing the knees into the tub necessitated more sponge baths versus tub baths. The limited range of motion in the hips in Case B lent to an added transfer after toileting for perineum cleaning.

Adaptations and equipment were in place for the encouragement of independence on the child's part, the maintenance of hygiene, comfort, and positioning. Adaptations included metal spoons verses plastic, extra liners in diapers, extra shirts, pillows for positioning, bowls with attached straws, curved spoons, straining spoons, bath chairs and extended shower heads.

It was also found that the larger pieces of equipment were serving in alternative functions. For example, Case A utilized the bath chair for television watching. This chair was preferred because of its reclining abilities. The potty-chair is reported to be quite versatile. "...we use that same potty chair because out of all the chairs that we’ve had, we’ve tried highchairs and everything, it has the best arm, elbow height ratio. We’ve tried a lot of chairs and that’s been the best one...." The potty-chair was also identified as an alternative positioning piece. It was reported as having a lower probability of creating pressure signs.

All three mothers report a desire for a lift to assist with transfers. All three mothers have attempted and dismissed the use of lifts in the past. The size and dimensions are reported as the rejecting elements... It was a big monster,"(Case B).

**Spasticity Encounters**

This theme clustered data that described situations and locations of spasticity. The categories of baseline spasticity encounters and increases in spasticity encounters did emerge. Baseline spasticity encounters refer to the physical locations of spasticity when the child was at rest. Increases in spasticity encounters relate to situations that elicit additions of spasticity beyond the baseline.
Baseline Spasticity

Although all children were diagnosed as spastic quadriplegia, the mothers all identified the distribution of tone differently. Case A identified both upper and lower extremities as being stiff. In addition the right shoulder, right elbow and right forearm were perceived as “most stiff.” Case B described the legs as most stiff, with emphasis in the “hamstrings,” knees, and hips. Case C referenced “the left arm and both legs” with the left arm as “most” involved.

All three mothers reported encountering baseline spasticity during undressing, dressing, bathing, transferring and positioning and feeding. The site and distribution of the spasticity was generally similar however variations were described.

Dressing

In terms of undressing, only Case C reported one arm as concerning in relation to spasticity. Unanimously the mothers reported the “trunk down” or the legs as the site of the most spasticity encountered during dressing. Again, Case A reported the right hip and knee being held in “tucked” position during dressing. This mother goes on to report the difficulty in attempting to pull pants in particular under the “tucked” right knee and against the left and right inner thighs.

Case C explains a reversing situation that occurs between dressing and undressing. The hips and knees are the location the spasticity encounter during undressing while one arm and hand was the local of the spasticity encounter for dressing. “Pants” in dressing and undressing were most frequently mentioned as troublesome in relation to spasticity encounters of the hip and knee.

The ankles are fine. It’s just when you get to that point when you are getting near the knee and you are trying to pull the pants up ... and you are trying to get more slack, then when you are trying to pull them up you want them to come all the way up and you get to the point where you are still pulling and their lagging behind because the legs are closed because it is stiffer and then getting them back down (is the same procedure) (Case B).
Bathing

During the actual bathing process, Case C reported encountering spasticity in the left arm and both hips and knees. The perineum is also a site of the spasticity encounter during the actual bathing process and drying.
Increases in Spasticity Encounters

Autonomic

All mothers reported an autonomic component to increases in spasticity. Pain and temperature levels were associated with increases in spasticity. For example, Case A reported a generalized increase in tone with pain in the most spastic arm. A general increase in spasticity was also noted in Case C during the after bathing drying off process secondary to the child being cold.

Vicarious and actual excitement was related to generalized increases in spasticity. Case B described situations where the child’s vicarious excitation produced a generalized increase in tone.

Interviewer: What was the situation that created the most stiffness, like within the last 24 hours?
Mother: I would say that when she gets excited, like when she is laughing or like last night she was calling her brothers because she wanted them to come into the room (to watch the brothers play) so she was getting mad and she was getting stiffer.

Excitement about eating and the naming of certain favorite people were reported to generate increases in spasticity that caused a pushing back out of the child of Case A’s chair. Excitations from sudden noises or voices are said to generate an increase in tone in the otherwise uninvolved trunk and arms, in Case C.

Effort was described in connection to increases in limb tone. Specifically hip and knee tightening with the arm “contorting” was reported with attempts independent positional changes. Case B states… “…she would try to raise up or she would be try to keep herself in line. She just wasn’t as relaxed.” The effort of self-feeding, specifically the utensil or cup to mouth sequence, was also reported to produce tone increases in the arms and oral musculature.

Emotional

The child’s fear and worry of discomfort was unanimously reported as the primary contributor to an increase from the baseline tone level. The children were assessed by the mothers as anticipating possible fearful situations. “…she stiffens up as if she knows it going to hurt on the right side, just in case you might bump it or something” (Case A) The mother of Case A stated it was a “visual” anticipatory response. The
child of Case A developed a total increase in flexion spasticity upon the mother’s approach for a transfer or position change.

The caregiving situations that were most cited in connection to increases in spasticity (secondary to the child’s worry of discomfort) were that of transferring and positioning. Mother frequently reported that the children could sense insecure transfers or unstable positions. A discourse with Case A demonstrates the relationship of tonal increases with the anticipation and the fear of falling or being dropped.

Interviewer: “Does she stiffen up more going from the bed to the chair than from the chair to the truck”?

Mother, “More from the chair to the truck.”

Interviewer, “Why do you think it’s more”?

Mother: “Because you’re going from a low lift to a higher one.”

Interviewer, “Why do you think she gets more stiff with that”?

Mother, “Because it’s further for her to fall.”

Interviewer, “She is fearful”?

Mother, “Yea.”

Interviewer, “When she does it, does she do that total body stretch”?

Mother, “She won’t stretch, her body just locks and locks in a sitting position.”

Transferring and positioning in combination with bathing was most frequently met with remarkable additions to the base level of spasticity in all three cases. For example, Case A reported significant increase in spasticity levels in the whole body with the specific inclusion of the arms when simply adjusting the supporting pillows during the sponge bath. There were also increases in spasticity with the transfer going into and out of the tub. “she would stiffen up when it was time to get in there, when I would go to lay her in, she would stiffen up, I mean stiff as a board, and then the same when you would take her out.” (Case A). Case B reported an increase in spasticity when the child was positioned on the bathroom counter prior to the bath. Because the child of Case C sits independently in a bath chair the mother reported increases in total body spasticity in attempts to “catch” herself from falling from side to side.
Essence Disclosures

This is the theme which clustered data in regards to the parental vista on caregiving for children with spasticity. The data gleaned as the pith of the experience assembled here. Three sub-categories emerged, frustration, workload, and worry.

Frustration

All three mothers expressed issues with frustration with the care giving process. The restrictions associated with limited range of motion, the inconveniences with the care giving process and difficulty accomplishing standards of care giving were all cited as sources of frustration.

The frustrations that were associated with limited range of motion were primarily identified in conjunction with dressing and bathing. One mother actively described the frustration as "...her pulling and you pulling," during dressing and bathing. Two mothers frequently returned to the nature of having to "pry" the legs apart for dressing and bathing. Range of motion limitations in regards to transfers were in addition identified. Mothers indicated that if they could only "straighten out" a particular limb during transfers or positioning, one source of frustration could be eliminated.

The issue of the inconvenience of care giving was in connection to discussions of frustration. The elements of inconvenience were frequency/repetitiveness and workload. These elements were said to interfere with the mother's ability to purely do the task-at-hand. For instance, all three mothers implied that the set up required for bathing was inconvenient. "...it’s because if I could get her to the tub, then I can get everything at one time..." (Case A). Case B related the need to having all items in place before doing the undressing which preceded the bath because she would never turn her back once the process was initiated.

Not being able to get the children clean to their standard or not knowing if the children are clean were all sited as areas of frustration. The hair was specifically identified as frustrating. Mothers related the difficulty of cleaning the hair along with the frustration of not knowing if the hair was absolutely clean. When asked to expound the this scenario Case A stated:

I don’t feel like I can get her clean enough just giving her a sponge bath. You just don’t feel like you’re getting them clean when they’re just laying there and you got to rotate them from one side
to the other and like that. I would rather be able to put her in the tub and then I can wash her two or three times if that's what I want to do.

A discourse with Case B demonstrated a relationship between limited range, inconvenience, and attempts to clean. Here she related that after toilet cleaning required an additional transfer onto an alternative surface (inconvenience) because of the extremely limited range of motion in the hips made it otherwise impossible.

Workload

The physical cost of workload was unanimously and repeatedly disclosed by the mothers. The comments of workload identification were characterized by "...it's time consuming," and "it drains you." Case C held to "the physical cost" as the overarching comment on care giving throughout the interview." When relating the essence of care giving for the spastic child, Case B stated, "...Yes definitely, to me the hardest part...is dressing, undressing and toileting."

The citation of workload issues was most frequently related to transferring and positioning. The weight of the child or mother, the height of the mother and the back health of the mother were all physical characteristic that were identified as contributory to workload. Task characteristics of frequency, time, and repetitiveness were primarily expressed.

Worry

The category of worry was recursive and most weighted disclosure Characteristically, worry was grouped into areas of health and hygiene, the unknown, feeding, services providers and non-intentional inflicted discomfort.

Two mothers reported health and hygiene worries. The worry of the children not being clean is specified. The method of sponge bathing was connected to this worry. The inabilities to thoroughly rinse the child, bathing in bed, and/or the difficulty of the perineum, are all expressed contributors to this item. One mother expressed worry in regards to "odors coming out." The exposure to microorganisms was also expressed.
...she came home from school, she caught ringworm before, so I am always paranoid ... because the kids they touch on her…. I worry about bacteria and a lot of times I encourage the kids to hold her hands; ... I don't want her to bring nothing home (Case B).

Worry of the unknown outcome of spasticity was expressed. This worry was in relation to parental awareness of spasticity and its potential disfiguring and contorting effects. The never ending waiting to see if disfigurement will occur or if additional or more severe changes in the physique will occur was a point of worry.

Well it bothers me not knowing what's wrong with her. Like I can see how she is right now but is there something going on that I can't see right now. I would like to know if she going to get tighter and locked? Is the way that she is tight right now going to change her body more over time? So, I do wonder about that (Case A).

Choking was expressed as a significant worry in Case A. There was choking that occurred at night was most disturbing. These episodes, which were preceded by a span of gagging and concluded with emesis, were of a constant worry. Choking that is associated with drinking was less concerning.

Issues clustering around the unintentional infliction of discomfort were the most pronounced in the area of worry. Curiously, this worry was often reported in the terminology of the senses. The sounds of the words crack and pop, and the feel of resistance were all expressed.

Inflicted discomfort of a specific body part or the body in general was identified. One mother reports specific irritation of the vaginal area secondary to the tightness of the perineum, with soap during bathing. The hair being irritated with the pulling and tugging against the spasticity of upper body dressing was also expressed. General body discomfort worry was reported in relation to temperature. Temperature worries included the children becoming cold during bathing or undressing.

Unanimously, the mothers herald the worry or dropping their children or the children sustaining a fall, more that all other expressed worries. The drops or falls are most feared during transferring and positioning. There was also the element of the mother's awareness of vulnerability during transferring and
self-indictment in the event of a drop. The necessity and frequency of transferring and positioning coupled with the core vulnerability of the task was the containment of these mothers' worry.

One mother expressed concern over the competence of a school service provider to perform frequent and efficient transfers. The scenario included a small stature school personnel. The possibility of the child being dropped during toileting transfers was a daily worry.
CHAPTER V
DISCUSSION and CONCLUSION

Discussion

I have attempted to uncover the concerns of parents/caregivers of children with spasticity. The data identified two spasticity encounter categories. First there is baseline encounters. This area clustered data that identified the location of spasticity when the child is at rest. Secondly, the increases in spasticity encounters category clustered data in regards to situations that precipitated an increase in spasticity from the baseline. Links were observed between the Spasticity Encounter theme and the Nature of Caregiving and Disclosures themes.

Baseline encounters with spasticity were most frequently engaged during dressing and bathing. The Nature of Caregiving theme also identified dressing and bathing as the most frequent and repetitive of the caregiving tasks. The most frequent identified sites of baseline spasticity were the hips and knees.

From the perspective of the Disclosures theme, the knees and hips were also the most identified locations these mothers were worried of inflicting pain. Therefore, the situation is that these mothers are experiencing worry of inflicting pain while performing the most frequent and repetitive of care giving tasks (dressing and bathing).

Increases in spasticity encounters were most frequently combined with care giving tasks that involved transferring and positioning. The increases in spasticity were generally distributed throughout the child’s body. From the perspective of the Nature of Care giving theme, transferring and positioning were most identified as the care giving task associated with the most workload. The Disclosures theme also identified transferring and positioning as the care giving task that the mothers most worried of inflicting pain.

The situation here, therefore, is that mothers are worried of inflicting pain by dropping the children while they perform the care giving task of the most workload. Congruently the children are experiencing increases in spasticity from fear of being drooped.
Conclusion

The concerns that have been uncovered can be categorized in the three emerged themes of Nature of Caregiving, Spasticity Encounters and Disclosures. Overall it appears that the mothers are performing caregiving tasks that are concerning in regards to the frequent and repetitive nature of the tasks, the ever presence of the condition of spasticity (both baseline and increases) and the frequent state of worry.

Limitations

One of the strengths of the study was also in part a limitation. Given the homogenous nature of the children, all spastic quads, other possible configurations of spastically were not sampled. For example, what is the nature of care giving for diplegia or hemiplegia? Suggestions for future study would be the subject selection of specific alternative spasticity distributions.
Date: September 6, 2002

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    Lynda Johnson-Cross, Student Investigator for thesis

From: Mary Lagerwey, Chair

Re: HSIRB Project Number 02-07-12

This letter will serve as confirmation that your research project entitled “Investigation of Parental/Caregiver Concerns of Children with Spasticity” has been approved under the exempt category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you may only conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: September 6, 2003
REFERENCES


In cerebral palsy. *Journal of the American Medical Association, 265*(11), 1418-1422.


