The Impact of Infant Disability on Maternal Perception of Stress

Lynn Singer and Kathleen J. Farkas

Twenty-seven mothers of infants and children with long-term tracheostomy were given a modified version of the Impact-on-Family Scale as part of a study designed to describe maternal perceptions of the impact of infant disability on various components of family life. Maternal perceptions of intensity of stress in different life areas were also examined as a function of salient medical, social, and demographic factors associated with the child's disability. Mothers report a high degree of stress in caring for their young disabled children, most notably in financial status. Mothers also report a strong sense of mastery in learning to care for their children. Several medical and demographic factors related to degree of maternal stress are identified.

Successful adaptation to chronic illness or disability for infants and young children is thought to be at least partly a factor of the family's ability to cope with the stresses involved. Recent medical advances have increased the need for home care for chronically ill or disabled infants and toddlers, particularly survivors of high-technology neonatal intensive care units. Medical advances have also increased the numbers of professionals who come into contact with caregiving families. These families include not only those whose children are in neonatal intensive care units, but also families who care for their chronically ill and disabled children at home. Physicians, nurses, social workers, and allied health professionals encounter increasing numbers of developmentally disabled infants in pediatric acute-care and rehabilitation settings. Recent legislative changes also require that infants and younger children with developmental disabilities be assimilated into local school programs. Thus, early child care educators and teachers will also need information about how families cope with the stresses of caregiving in order to develop appropriate intervention programs.

While there exists a growing body of research on the long-term effects of disabilities on children and their families, there are few guidelines for practitioners interested in strengthening parents' abilities to manage their caregiving roles. An understanding of caretakers' perceptions of the stresses related to such care is essential to foster caregiver coping and to avoid prolonged hospitalization for children. Greater understanding of specific influences perceived by caregivers as exacerbating or ameliorating stress related to caring for developmentally disabled or chronically ill infants can aid family workers who must provide support to caregivers.

Previous studies have suggested that parents of children with developmental disabilities, particularly mothers, experience greater stress and less psychological well-being than controls (Bradshaw & Lawton, 1978; Breslau & Davis, 1986; Breslau, Staruch, & Mortimer, 1982; Burden, 1980; Friedrich & Friedrich, 1981; Kazak, 1987; Tavormina, Boll, Dunn, Luscomb, & Taylor, 1981; Wilton & Renault, 1986). Additionally, some researchers have assessed the relationship of parental stress levels to relevant medical and social characteristics of the child and family. Chetwynd (1985), for example, found higher stress levels in mothers of intellectually disabled children to be related to child temperamental factors as well as socioeconomic status. Social class and maternal level of anxiety were found to be the best predictors of stress in mothers of seriously ill hospitalized children in another study (Wyckoff & Erickson, 1987). Social support networks have also been investigated in families with developmentally disabled and chronically ill children (Kazak & Marvin, 1984; Kazak, Reber, & Carter, 1988) and found to relate to levels of stress.

This article further explores these issues by (a) describing maternal responses to an empirically based questionnaire designed to measure the impact of infant disability on various components of family life and (b) relating mothers' perceptions of degree of stress in different areas of their lives to medical, social, and demographic factors associated with the child's disability.

Subjects and Method

Subjects were children who had previously received tracheostomies. Tracheostomy is a medical procedure which requires implantation of an endotracheal tube as a means of providing an open airway for breathing. Duration of tracheostomy in infants can persist for lengthy periods of time, ranging from several months to years. Previous studies have demonstrated that infant tracheostomy is a chronically handicapping condition which frequently occurs in the presence of other disabilities, such as mental retardation or physical disability (Singer et al., 1989). However, developmental outcome can vary greatly. Since tracheostomy inhibits vocalization during the early developmental period and because infants with tracheostomy often endure long hospitalizations and chronic illness, they are at risk for delayed growth, speech-language impairment, and behavioral and social problems (Hill & Singer, in press). Singer et al., 1989). Several aspects of

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caring for an infant with tracheostomy can be perceived as stressful for parents. Infants with tracheostomy are at greater risk for infection; require specialized and expensive medical equipment for cleaning and changing the tracheostomy tube, and must be shielded from ordinary play activities, such as water or sand play, because of risk of airway obstruction. Parents with children with tracheostomy frequently cannot find baby-sitting or day-care services (Ruben et al., 1982).

The sample was comprised of 27 mothers whose children had experienced tracheostomy of at least 3 months duration in infancy and were seen as part of a cross-sectional follow-up of developmental outcome. All infants were recruited from a tertiary care, university pediatric hospital to which all infants requiring tracheostomy in a tri-county region were referred. While tracheostomy often occurs concomitant with other disabling conditions (Singer et al., 1989), children in the present sample were those who did not have severely impairing accompanying conditions, such as cerebral palsy and mental retardation, but represented the healthiest subgroup of a larger sample of infants.

All mothers were requested to complete a modified version of the Impact-on-Family Scale (Stein & Riessman, 1980). The original scale was designed to quantify the impact of childhood illness on family functioning in a 24-item, Likert-type questionnaire. The scale factors into four subscales which measure the impact of chronic illness and disability on various aspects of family life, namely; financial status, family/social interaction, subjective distress, and a positive sense of mastery. A total score also yields a general measure of impact. The normative sample for the scale consisted of 100 urban mothers of lower social class whose children were included in a longitudinal study of chronic illness. Cronbach’s alpha, a measure of reliability, ranges from .60 to .86 for individual subscales and .88 for the total scale.

As part of the present study, medical, psychosocial, and demographic factors were documented through retrospective chart review and interview at time of follow-up. These factors included race, sex, birth order, birth weight (in grams), gestational age (by Dubowitz Score) (Dubowitz, Dubowitz, & Goldberg, 1970), marital status, total number of weeks hospitalized, and duration of tracheostomy in months. Severity of illness at birth and through the first month of life was measured through the Postnatal Complications Scale (PCS) (Littman & Parmelee, 1978), which rates the presence or absence of 10 possible early medical conditions. These include respiratory distress syndrome, mechanical ventilation, surgery, hyperbilirubinemia, infection, anomalies, metabolic disturbances, convulsions, temperature disturbance, and feeding difficulties. Scores derived from the PCS range from 50-160, with higher scores indicating more optimal functioning.

As a measure of illness severity later in the first year of life, the Pediatrics Complications Scale (PedsCS) (Littman, 1979) was also derived from chart review. This scale also quantifies pediatric findings in the first 9 months of life by noting the presence of medical problems such as abnormal growth rates; occurrences of illness, injury, or hospitalization; and physical and neurological problems. Both PCS and PedsCS scores have been found to have significant, positive relationships to each other (r = .21, p < .05). The PCS also has been found to relate positively to the Obstetrical Complications Scale (OCS) which measures events related to maternal medical history and those immediately concurrent to labor and delivery. The PedsCS has been shown to relate to developmental outcome in samples of preterm infants (r = .27, p < .01) and infants with tracheostomy (r = .19, p < .05) (Littman & Parmelee, 1978; Singer, Hill, & Doershuk, 1988).

Presence or absence of neurological problems was specifically noted, including the following: hydrocephalus, seizures, intraventricular hemorrhage, neonatal seizures, apnea requiring a respirator, asphyxia with Aggar less than 6 at 10 minutes, multiple malformations, CNS syndromes, abnormal CT scan, and neurosensory abnormalities. In the present study, subjects with major neurological problems (i.e., asphyxia, CNS syndromes, multiple malformations, and primary neurosensory abnormalities) were excluded. Socioeconomic status was measured through the Hollingshead two-step method (Haug, 1977, Hollingshead, 1957).

Item analyses and descriptive statistics were used to describe maternal report of degree of stress across dimensions of the modified Impact-on-Family Scale. Correlational analyses were used to assess the relationship of medical, psychosocial, and demographic variables to mothers’ perceived impact of their children’s disabilities on family experience.

Results

Of a total sample of 32 27 children (15 males, 12 females, 19 white, 6 black) were seen for follow-up at a mean age of 4.0 years (SD = 2.5, Range = 11 months -12 years; Most families were middle class (70%). Twenty-six percent of the children came from single-parent homes. Almost half the sample were preterm; 27% were of very low birthweight. At birth, 79% of children had significant medical complications, with PCS scores under 90. Forty-eight percent had neurological complications ranging in severity from infant seizures to mild transient hemiparesis. The children had spent long periods in the hospital as infants (X = 29 weeks; SD = 31; Range = 2-104 weeks) and had retained their tracheostomy tubes for lengthy periods of time (X = 32.7 months; SD = 32; Range = 3-146 months).

Mothers reported a high degree of stress related to caring for their young children with developmental disabilities, as indicated by their responses to the Impact-on-Family Scale. Percentages of agreement with statements on the scale are presented in Table 1, in descending order of agreement rate for this sample. Percentages of agreement with individual scale items represent those mothers who agree or strongly agree to those statements. The mean total score for the sample was 58.8 out of a possible 96 points (SD = 11.6, Range = 33-79). Means, standard deviations, and ranges for each subscale are as follows: Financial (X = 10.2, SD = 2.8, Range = 4-16); Family (X = 20.5, SD = 5.7, Range = 10-34); Personal (X = 14.2, SD = 3.8, Range = 6-24); Mastery (X = 7.9, SD = 11.8, Range = 5-41); Sibling (X = 11.7, SD = 3.5, Range = 5-18).

In keeping with other research, respondents reported that the child’s disability affected all aspects of family life. Problems with family and social interaction and with finances were those cited by the majority of the mothers in this sample. The most salient negative impact involved financial status. Sixty-seven percent of respondents felt that their child’s disability caused financial problems for the family. 60% felt that this time was lost from work because of the necessary care, and 59% stated that additional income was needed to cover October 1989
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Married caregivers felt more financial stress and more stress with family and social interactions. Being married was also associated with higher levels of subjective distress. Surprisingly, higher social class was correlated with higher levels of subjective distress.

Discussion

Parental marital status and severity of medical complications appear to be critical demographic and medical variables affecting family life with a disabled child in this sample. Mothers whose children are more severely disabled experience more financial problems, more stress with family and social interactions, and more subjective distress. Other medical factors, namely the presence of neurologic complications and greater severity of illness at birth, have negative associations with maternal sense of mastery. Longer duration of disability is also associated with an increased sense of subjective distress.

This study explores maternal perceptions of stress in caring for a disabled infant and related intensity of stress in different family areas to specific factors in the child and family. As would be expected, mothers in this sample express a high level of stress related to the experiences of caring for their disabled children. Noteworthy, however, is the finding that these...
mothers also express feeling a high level of mastery related to caregiving. This finding may be related to a bias in sample selection in which only mothers who were coping adequately responded to the questionnaire. Thus, mothers who may have been depressed or bitter may have been less likely to respond. The high level of mastery may also be related to a response bias toward socially desirable answers. The possibilities of bias are suggested in the unanimity in the sample of agreement to the statement "Learning to care for my disabled child has made me feel better about myself," and the high rate of agreement with the statement that family networks have been helpful to the mothers in this sample. The finding also suggests that many mothers of young, multiply disabled children find meaning and enhanced self-esteem in coping with caregiving despite the stresses involved, since the response rate to the questionnaire was quite high (85%). Other studies have found high rates of agreement with similar positive statements in samples of children with cystic fibrosis (Phillips, Bohannon, Gayton, & Friedman, 1985) and children with myelomeningocele (Kazak & Clark, 1986). The present data, then, can provide information about the stresses and supports associated with more adaptive coping in families with disabled infants.

The significance to parents of the financial costs of care are highlighted in several different ways within the study: Mothers report concern about financial problems and the need for additional income for medical expenses. Greater financial stress is also felt by married, as opposed to single, mothers. Since single mothers in the present sample were all of the lowest social class and supported by Medicaid for their children's health care needs, the actual impact of financial stress may have been less, despite their lower socioeconomic status. Thus, working or middle-class families may be most affected by the financial stresses of their children's health care needs because they do not have access to specialized medical care and because insurers are increasingly covering smaller proportions of medical and rehabilitation services.

Working- or middle-class families are more likely to depend upon two incomes to meet the family budget regardless of medical expenses. The fact that a majority of mothers report that time was lost from work and that a quarter of them said they either had to cut down or stop working because of their need to care for their ill child highlights the financial pressures on working- and middle-class families. It is important that health care professionals recognize the increasing numbers of mothers with infants and young children who work outside the home and consider the economic strains which occur when the caregiver role interferes with maternal ability to contribute to the family's income. This becomes particularly important when the additional funds are most needed to cover the child's medical and rehabilitative care.

Married caregivers in the present sample may also have experienced other stresses in addition to the financial ones noted. While the supportive aspects of the marital partnership are emphasized in the Impact-on-Family Scale, it does not address the possible strains of that relationship, and its possible negative impact through the time and energy required to maintain a relationship, or to care for additional children.

In particular, the present sample is representative of growing populations of disabled children who did not survive previously, but who live today dependent on a range of technological services and medical equipment. These children have intensive rehabilitation needs in the face of shrinking health care benefits. Family life specialists need to be aware of the financial burdens placed on even middle-class families and help parents advocate for innovative ways to obtain support. In the present sample, for example, one insurer paid a mother's salary to quit work to stay home to care for her chronically ill infant, as well as paying for additional nursing care, since that arrangement was less expensive than continued hospitalization.

The finding that higher social class is related to greater personal stress for mothers of developmentally disabled infants may be due to the greater financial burden assumed by families with higher social class than by poorer families in the present sample. Wyckoff & Erickson (1987) found lower social class to be related to higher stress in their large sample of seriously ill children. Half the children in the present sample had neurological sequelae shown to be associated with intellectual deficits in our other studies (Singer et al., 1989). Parents with higher educational levels in this study may have experienced more stress due to their understanding of the long-term consequences of neurological problems in their children.

Finally, mothers with children who had neurological disabilities who had more medical complications, and whose disabilities were more chronic experienced greater problems in coping with their children's care. While this finding corroborates intuition, it underscores the importance of maintaining family support beyond the acute stages of illness or disability.

Implications for Practice

As medical science continues to advance, more children with disabilities will survive birth and live at home. Increasing numbers of allied health care professionals and child educators, both inside and out of the acute care setting, will need to develop strategies for addressing parental concerns and enhancing parental abilities to cope with the stress of care. Central among these strategies must be a focus upon the promotion of mastery and recognition of the strengths as well as the stresses of the caregiving parent. The use of mutual help approaches to improve social supports has been touted as an effective way to develop and enhance coping skills (Gartner & Reissman, 1977; Powell, 1987; Silverman, 1978).

Mutual help, which involves the use of peer counseling, educational seminars, small groups, and social support with or without professional leadership, is not a substitute for professional care and cannot fill the gap when professional services are inadequate (Silverman, 1988). However, the strength of mutual help in promoting mastery involves elements of social support which only peers can provide. Borkman (1976) emphasizes that people seek help from those with similar experiences when the help they need is not available from families, friends, or professional helping networks. The social support elements of mutual help approaches, such as learning that one is not alone in coping with the care of a child with a disability; sharing bits of practical information; learning to deal with feelings of intimidation with professionals; and breaking feelings of isolation, are all important in the development of a parent's abilities to solve problems and achieve a sense of mastery (Caplan. 1981). Many professionals working with families of children with disabilities have turned to mutual help approaches.
as evidenced by the fact that Sudden Infant Death Syndrome (SIDS) groups and Parents Experiencing Premature Birth groups are sponsored in hospital settings. Mutual help approaches, however, are not a panacea for enhancing mastery for all mothers of children with disabilities. Careful attention is needed in when, how, and why a professional uses a mutual helping strategy. As these data show, mothers with children who had more medical complications and whose disabilities were more chronic, experienced greater problems in coping with their children's care. Introduction too early or without preparation to a group of parents with less severely disabled children may impede rather than enhance mastery. Similarly, mothers who are brought into groups in which parents are coping with children with more severe disabilities may experience feelings of guilt and alienation as a result.

Early hopes that an infant may "grow-out" of a disability are frequently unfounded. Parents who are facing the long-term implications of a child's disability or illness may need to grieve and deal with their anger once the acute, life-threatening aspects of an illness are resolved (Heisler & Friedman, 1981). Often, this process occurs at a time when earlier supports, such as those provided in the acute-care hospital, are no longer available. Acute-care professionals who have early contact with families need to recognize this process and develop follow-up contacts and strong working relationships with community agencies and groups. Professionals, especially teachers, working in the community, must learn more about the changing medical and psychosocial needs of developing children with disabilities and their families in order to help parents maintain and strengthen their feelings of mastery.

Not surprisingly, parents of children who have even subtle neurological sequelae experience greater stress. Previous research has documented that such children have a greater likelihood of having behavioral and emotional problems, even in comparison to other physically disabled children (Rutter, 1977). Family practitioners and educators need to continue to update their understanding of the intellectual, behavioral, and emotional sequelae of infant neurological problems. Hyperactivity and attentional deficits, for example, which are associated with neurological problems, are likely to contribute to parental stress and may not respond to traditional treatment efforts. The child's behavior as well as the perceived ineffectiveness of the treatment may contribute to stressful parent-child interactions, inappropriate expectations for the disabled child with regard to discipline, school achievement, and behavior can put greater stress on the child and family.

The issue of family planning and the implications of chronic care on a couple's decision to have other children are also salient. Almost half of this sample of mothers identified ambivalent feelings related to the issue of having additional pregnancies. Genetic counseling through medical specialists can clarify the medical risk of having other children born with disabilities. However, professionals must also address the financial and psychosocial risks of additional pregnancies and help relieve anxiety and foster the family's adaptive and decision-making processes.

In general, there has been little research on parents' perceptions of stressors affecting their ability to care for a disabled or chronically ill infant. The present study suggests that social class, financial status, and severity and chronicity of a child's disability may affect maternal experience of stress. Since almost all respondents in the sample expressed the feeling that communication with their partners had been of benefit to them, fostering discussion of feelings and issues between partners may be an important focus of family intervention. A very high percentage of mothers rated their relatives as helpful, reiterating previous studies which have shown social support to be a relevant factor in a positive adjustment. Future studies which compare parents of handicapped or chronically ill infants to parents of healthy infants can help family practitioners understand how the early tasks of parenting differ in these groups. Longitudinal studies which assess stressors and parental coping strategies over time can help family life workers identify when and how intervention can be most optimally implemented.

Future studies should attempt to validate the present findings on larger populations of children with different illnesses. Specific conditions. These studies should distinguish between children with and without neurological conditions since these conditions may differentially influence parental stress through child behavioral difficulties. Finally, more research is needed on the perceptions of the fathers of children with disabilities and on how fathers' reactions to the stresses of caregiving are similar to or different from mothers' reactions so that interventions to decrease stress and increase mastery can reach those involved in the caregiving role.