Chapter 4

Description and Results of a Major Study of “High Tech” Home Care for Children with Chronic Health Conditions

This chapter describes the study by Fleming et al. (1993) of 898 technology-dependent children, on which much of this book is based. The purpose of this study was to further describe technology-dependent children and their families by examining various constructs and testing specific hypotheses. Four types of dependencies were the independent variables. Covariants were those that may affect responses but were not controlled by the investigator. These include duration of condition; regions of the country; demographic information such as economic status; cost of care; perception of resources; and type of agency (public/private) from which services were received. Dependent variables were the responses that result in terms of depression and satisfaction. Mediating variables were family stress, impact, social support, and the child's developmental level.

RESEARCH OBJECTIVES

The objective of the study was to create a database that will aid in further describing children who are technology dependent and being cared for in their homes. The specific aims were to

1. Identify selected demographic characteristics of children who are technology dependent and their families
2. Define home care of children who are technology dependent in terms of consumption of resources
3. Test selected hypotheses regarding the effects of the illness of these children on their families. (The hypotheses tested are listed here; see Figure 1 for the conceptual schema for testing the hypotheses)

*Hypothesis 1:* There will be a difference in the family level of stress in the families of ventilator-dependent (VD) children, children receiving IV therapy, children with daily dependence on specific support devices (SSDs), and children requiring monitoring of vital functions (VFs).

*Hypothesis 2:* There will be a difference in the impact on the family in the families of VD children, children receiving IV, children with daily dependence on SSDs, and children requiring monitoring for VFs.

*Hypothesis 3:* There will be a difference in the adaptive behavior of VD children, children receiving IV therapy, children with daily dependence on SSDs, and children requiring monitoring for VFs.

*Hypothesis 4:* There will be a difference in the social support of the family of VD children, children receiving IV therapy, children with daily dependence on SSDs, and children requiring monitoring for VFs.

*Hypothesis 5:* There will be a difference in the level of parent's depression for VD children, children receiving IV therapy, children with daily dependence on SSDs, and children requiring monitoring for VFs.

*Hypothesis 6:* There will be a difference in the level of satisfaction in VD children, children receiving IV therapy, children with daily dependence on SSDs, and children requiring monitoring for VFs.

*Hypothesis 7:* The type of dependence affects the family stress level, the impact on the family, the child's adaptive behavior level, and the amount of social support, which in turn determines the caregiver's level of depression and level of satisfaction.

4. Provide means for these data to be used by others in the development of recommendations for nursing practice as they related to the care of children who are technology dependent and their families.

Each of the four objectives incorporates several components.

1. To identify the select demographic characteristics of the population of technology dependent children who are cared for in the home and their families
a. Age/sex/race of children
b. Family constellation, structure, and dynamics
c. Etiology of conditions and diagnosis
   1) Permanent
   2) Temporary
   3) Length of condition
   4) Severity of condition
   5) Length of time cared for in the home
d. Type of dependency using classifications from Office of Technology Assessment (1987)

2. To define this population from perspective of consumption of resources
a. Units of nursing care regarding types of care given (i.e., suctioning, gastrostomy feeding, intravenous medications, etc.), those who give care (i.e., aide, L.P.N., R.N., etc.), and number and length of visits
b. Cost of care required and payment sources
c. Community and other resources
d. Family supports and coping resources
e. Public or private agency involvement

3. To determine the effect of the dependency on the family
a. The impact of care on the family
b. Social support for the family
c. Stress on the family (psychological and physiological)
d. Parent and sibling responses
e. Adaptive development behavior

4. To integrate this data into a form capable of supporting development of standards for nursing practice, education, and continuing support of nurses providing care for technology-dependent children and their families in the home settings

A technology-dependent/assisted child is defined as “one who needs both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability” (OTA, 1987, p. 3). The OTA delineated four separate populations, distinguished by their clinical characteristics. These definitions were used in this project. The groups are defined as follows:

Group I: Children dependent at least part of each day on mechanical ventilators
Group II: Children requiring prolonged intravenous administration of nutritional substances or drugs

Group III: Children with daily dependence on other device-based respiratory or nutritional support, including tracheotomy tube care, suctioning, oxygen support, or tube feeding

Group IV: Children with prolonged dependence on other medical devices that compensate for vital body functions who require daily or near daily nursing care. This group includes

- infants requiring apnea (cardiorespiratory) monitors
- children requiring renal dialysis as a consequence of chronic kidney failure
- children requiring other medical devices, such as urinary catheters or colostomy bags, as well as substantial nursing care in connection with their disabilities (OTA, 1987, p. 4).

Dependent variables were the responses that result in either depression and satisfaction. Mediating variables were family stress, impact, social support, and the child’s developmental level. Covariants were those that may have affected responses but were not controlled by the investigator. These include duration of condition, regions of the country, demographic information such as economic status, cost of care, perception of resources, and type of agency (public/private) from which services were received.

Study Design and Methods

The study was a descriptive survey. A purposive sample was obtained from families receiving services from both public and private agencies in 13 cities representing geographic census regions of the country. A structured telephone interview was conducted with the primary caregiver (parent or guardian) of the technology-dependent child. Children were between 3 months and 19 years of age and had been technology dependent and being cared for at home for at least 1 month.

In each of the cities, a nurse served as a coinvestigator/liaison consultant for the study. The areas were representative of the regions and subregions identified from the U.S. Census Bureau definitions. Data were obtained through a structured telephone interview conducted by the University of Kentucky Survey Research Center. The parents or primary caregivers of technology-dependent children were the subjects, and each was inter-
reviewed. The children represented a mixture of those receiving services from both public and private home health agencies. The children were also representative of all four groups of technology dependency as defined by the OTA (1987).

To avoid bias and logistical problems, a three-stage sampling procedure was used. At Stage I, each liaison consultant listed and briefly described a maximum of 10 home care agencies, equipment vendors, and tertiary care hospitals with pediatric home care units in his or her area that cared for technology-dependent children. Also at Stage I, the university research team selected a subset of these agencies for further sampling; criteria were the number and mix of children that reflected the groups of children defined as technology dependent by the OTA (1987). At Stage II, each liaison consultant worked with those selected agencies in compiling lists of families who were to be sampled and sent letters seeking participation in the study. Hence, consultants were primarily responsible for recruiting agencies, while selected volunteer agencies were responsible for recruiting volunteer caregivers. They avoided problems that would have occurred in attempting to satisfy numerous internal review boards on the issue of protecting patient privacy.

Each selected volunteer agency compiled two lists of names by using the following patient stratification:

**Strata A:** Children with a prolonged dependence on a medical device that is required to sustain life. Using the OTA manual, this included the following three groups of children:

*Group I:* Children dependent as least part of the day on mechanical ventilators

*Group II:* Children requiring prolonged intravenous administration of nutritional substances or drugs

*Group III:* Children with daily dependence on other device-based respiratory or nutritional support, including tracheotomy tube care, suctioning, oxygen support, or tube feedings

**Strata B:** Children with a prolonged dependence on other medical devices that compensate for vital body functions who require daily or near daily nursing care. This includes

- Children requiring apnea (cardiorespiratory) monitors
- Children requiring renal dialysis as a consequence of chronic renal failure
• Children requiring devices such as urinary catheters or colostomy bags as well as substantial nursing care in connection with their disabilities

Once these lists were constructed, each selected agency was requested to send information packets describing the purpose of the study (which had been provided to them) to a subset of the caregivers of patients on the lists. The number of names selected from each list was determined by the University of Kentucky research team; a systematic sample was the method for choosing names. The information packet contained a description of the purpose of the study and an addressed postcard. Caregivers, most of whom were parents interested in volunteering for the study, were asked to complete the postcard (name, telephone number, and child’s type of dependency) and mail it to the university research team. They were provided information about the study and told how their rights would be protected.

Stage III occurred once the postcards were returned. The final sample, with approximately 40 per strata per region, was made up of those who returned the postcards, indicating their willingness to participate. Each person was called to arrange a time for the interview. An interviewer, trained by team personnel, called at the scheduled time using the structured interview guide, which consisted of demographic information, select published scales, and investigator-developed questions. Permission had been obtained to use the select published scales. A protocol approved by the Human Subjects Review Committee was followed to ensure that subjects’ rights were protected. The interview guide was pilot tested before being use in major study.

**Measures**

Measures obtained in the study follow.

*Family Inventory of Life Events (FILE)*

This self-report assessment-designed instrument measured family stress by recording normative and nonnormative family demands that the family might have experienced in the past year (McCubbin & Patterson, 1981). The latest adaptation of the inventory (Form C) was used. This form contains nine subscales and includes items that focus on family demands
and strains associated with a chronically ill family member. The total index is reliable with a Cronbach alpha of .81. Tests of validity indicated the total inventory score is significantly and inversely correlated with measures of changes in health states, and that this score is correlated significantly with measures of family functioning.

**Impact on Family Scale**

This scale was designed to measure the effect of a child with a chronic condition in producing change in the family (Stein & Riesman, 1982). Impact was conceptualized as the effects of the child’s illness on the family system. Four dimensions were theorized as relevant: economic (changes in the economic status of the family), social (quality and quantity of interactions with others outside the family), familial (quality of interaction within the family unit), and strain (subjective burden experienced by the primary caretaker). The scale is seen as reliable enough to detect a change in the family’s lifestyle. The construct validity had been extended, and the analyses of the data of 209 cases suggest that the Impact on Family Scale was tapping the construct it was designed to measure.

**Social Support Inventory (SSI)**

This scale provides an index of social support that was available and that the caregiver received from various sources as perceived by the caregiver (McCubbin & Thompson, 1987). Reliability was reported at .82 level.

**Center for Epidemiological Studies Depression (CES-D) Scale**

This 20-item scale assesses depressive symptomology over the previous 7-day period. It attempts to gauge the feelings of the caregiver within the past week. Internal consistency with this scale had been demonstrated at the .85 level or above (Radloff, 1977).

**Family APGAR**

Caregiver satisfaction is measured with this five-item scale developed by Smilkstein (1978). It was used to obtain information on caregiver’s satisfaction. It had been found to have satisfactory internal consistency reliability (alpha = .80), test-retest reliability (r = .83), and validity in previous research (Austin & Hubety, 1989).
Child's Development

Parents were asked questions about their children's development. The caregiver was asked if the child's development had been assessed by a health professional and, if so, if there were developmental problems. The caregiver also was asked to evaluate the child's level of functioning compared with other children of the same age. If delays were present, they were also asked to identify the area or domain of the delay.

Demographics

The child's age, gender, race, primary medical diagnosis, and technology dependency were recorded. Also recorded were the caregiver's age; relationship to child; education; marital status; work status; residence; number of children in the family; religious preference; family income; transportation; and resources.

An advisory committee composed of nurses serving as liaisons/consultants to the project and who are involved directly or indirectly in the delivery of home care and parents of children who are technology dependent and receiving home care provided input to the principal investigator about the proposed methodology. A pilot study was conducted to ensure that the data proposed and the approach to be used to obtain information about the development of children would be obtainable. The database was to be used to develop standards for practice, establish professional policy regarding nursing practice, and continue support of nurses providing home care to technology dependent children with chronic conditions and their families. The database may also be useful in planning for continuity of care, interdisciplinary collaboration, curriculum development for nursing programs, and further research. The database may also be used to disseminate information that could provide insight into means of supporting these families. The study was approved by the Institutional Review Board of the University of Kentucky.

FINDINGS

Demographics

The primary caregivers of 848 technology-dependent children were interviewed. The caregivers ranged in age from 17 to 65 years with 49.3% being
between 25 and 34 years. Eighty-eight percent of the children were cared for by their mothers, with the other 12% of the caregivers being fathers, foster parents, adoptive parents, or others. Seventy-seven percent of the caregivers were married; 42% were currently working outside of the home and 58% were not.

Fifty-seven percent of the children were males and 43% were females: 10.7% were ventilator dependent, with a mean age of 6.9 years ($SD = 5.4$); 13.8% were IV dependent, with a mean age of 6.7 years ($SD = 5.0$); 50.1% were dependent on devices such as feeding tubes or oxygen support, with a mean age of 4.0 years ($SD = 3.9$); and 25.4% used monitoring devices, with a mean age of 2.1 years ($SD = 3.7$). Their primary medical diagnoses varied (see Table 5.1 in Chapter 5 for overall description of demographics of the 848 participants).

**Hypotheses 1**

A significant difference was found among the mean profiles of the four dependency groups on the nine subscales of the Family Inventory of Life Events (MANOVA $F = 5.98$ based on 27 and 2,439 degrees of freedom, $p = 0.0001$). To explain this significant difference further, a one-way analysis was used to compare means among the four types of dependency groups for each subscale. Significant differences were found for three subscales—family life change, pregnancy and childbearing strains, and illness and family care strains.

**Hypothesis 2**

A significant difference was found among the four types of dependencies on the mean profiles for the subscales of the Impact on Family (MANOVA $F = 9.43$ based on 12 and 2223 degrees of freedom, $p = 0.0001$). A one-way ANOVA test showed that the means vary among the subscales for financial burden, family social impact, and personal strain.

**Hypothesis 3**

A significant difference was found in the variance of adaptive behavior of children with the type of dependency (Chi Square $= 132.8$, 3df, $p = 0.001$).

**Hypothesis 4**

Mean social support was found to not vary significantly among the four types of dependencies.
Hypothesis 5

Mean depression scores did not vary significantly among the four types of dependencies. A significant correlation was found between the family stress score (total score of the nine subscales of the FILE) and the actual depression (CES-D) score ($r = .47, p < 0.0001$).

Hypothesis 6

Three measures of satisfaction were made, two of which were not found to be significant. The third measure, satisfaction with the quality of the caregiver’s life in general, varied significantly among the four types of dependencies (Chi Square = 31.2, 3 df, $p = 0.0001$).

Hypothesis 7

While the type of dependency affects family stress level, impact on the family, adaptive behavior level of the child, and the amount of social support, once these factors are controlled for by type of dependency, there is basically no effect on the caregiver’s level of depression or satisfaction. A logistic regression model was used to predict the log odds of respondents with a CES-D score of 16 or above (indicating signs of depression), a Family APGAR score above the median (indicating satisfaction) reporting a great deal of satisfaction with having enough finances to provide an adequate level of care for their child. The results of this analysis show that the type of dependency is not a significant predictor of depression, nor for three of the four measures of satisfaction. It is, however, a predictor for respondents who reported a great deal of satisfaction with their quality of life. This difference is reflected in the percentage of respondents of VF families reporting a great deal of satisfaction compared with VD, SSD, or IV family respondents.

DISCUSSION AND CONCLUSIONS

Findings from this study show caregivers of children who are technology dependent and receiving home care are predominantly white and middle class. The financial burden and social impact on the family and personal strains vary depending on the type of dependency. Children whose vital functions (VFs) are monitored are the least likely to have developed as
other children but are not as much a financial burden and have less social impact and cause less personal strain on the family. Development of children who have specific supportive devices (SSDs) is similar to that of other children. They, too, do not cause financial burden and have less social impact and cause less personal strain on the family. Ventilator-dependent (VD) children and those requiring IV therapy cause financial burden, have a higher social impact, and cause more personal strain on the family than do VF and SSD children.

Depression among caregivers does not vary significantly among the four types of dependencies. Caregivers of IV nutrition or drugs tend to show greater depression than any other group. Depression also seems to be more likely if a child is dependent one or more years.

Satisfaction varies significantly with caregivers. Caregivers who were the least satisfied with care were those with VD children and IV children.

The quality of life for a child who is technology assisted or dependent and their caregivers apparently is affected by persons who work with them in their home. Nurses made up the largest group of professionals who worked with these families. The caregivers expressed that more knowledge was needed about their child’s condition and how to care for the child before the child was brought home. There seems to be a need for more definitive discharge planning and teaching of care that family caregivers will be expected to know before the child goes home.

It is likely that more children who are technology dependent will receive care in their home, as it appears that it is more cost-effective. Nurse educators are encouraged to include content in the curriculum that will help future nurses understand how to work with family caregivers in managing children who are technology dependent and cared for at home.

This study is limited in that it could have had more Hispanic caregivers, but a Spanish version of the questionnaire had not been prepared. It is recommended that further studies of children who are technology dependent include a Spanish version so more Hispanic caregivers can participate. The small number of low socioeconomic participants and African American participants suggests that children who are technology dependent in these families may not be cared for in their homes. In future studies about this population of children, every effort should be made to include families that represent the diversity in the population of the country. Follow-up studies on the status of families and these children are encouraged. The implications for longitudinal research on these families and their children who are technology dependent are tremendous. Such studies would add to knowledge about the quality of their lives and their needs.
Follow-up Study

During the year 2000, a follow-up study was conducted of a random sample of the 848 primary care givers of children being cared for in their homes who were technology dependent, and were age 3 months to 19 years when they were interviewed in the early 1990s. A telephone interview using a structured interview guide to determine the status of the children and family was the method used to obtain data. The Internet was used extensively to locate the families as most no longer resided in the homes where they were contacted initially. The findings of the follow-up are described in Chapter 1. Most of the caregivers reviewed children who no longer needed a technology device. Those whose children still needed a device also required professional health care assistance; all of whom except one was a nurse. The children’s development academically, behaviorally, and socially compared with children in their own age (the largest number were ranked about average).

REFERENCES


