Canadian Journal of Nursing Research, 1998, Vol. 30, No. 1, 71–95

Stressors in Families with a Child with a Chronic Condition: An Analysis of Qualitative Studies and a Framework

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Cet article propose un cadre détaillé fondé sur la recherche et cliniquement utilisable des facteurs de stress et des tâches aux familles qui comptent un enfant atteint d'une maladie chronique. Les termes facteurs de stress, tâches, défis, préoccupations et problèmes sont couramment employés pour décrire les peines et les joies que vivent ces familles. Du fait de leur caractère unique et évolutif, il est difficile d'en donner une description globale. L'article décrit brièvement les premières étapes d'élaboration du *Burke Stressors and Task Framework for Families with a Child with a Chronic Condition*, ainsi que ses applications cliniques. La dernière étape de l'élaboration du cadre est décrite plus en détail. Il s'agit d'une « méta-analyse » des résultats de recherche qualitative qui ont confirmé les éléments du cadre. Des étapes de recherche ultérieures et des utilisations cliniques du cadre sont proposées en conclusion.

This article presents a comprehensive, research-based, clinically useable framework of stressors and tasks for families with a child with a chronic condition. Terms such as stressors, tasks, challenges, concerns, and problems are commonly used to describe the struggles and triumphs of these families. Their unique and changing nature has complicated comprehensive description. The steps in the early development of the Burke Stressors and Tasks Framework for Families with a Child with a Chronic Condition, and its clinical uses, are briefly described. The final step in the development of the Framework is discussed in more detail. This was a "meta-analysis" of qualitative research findings that confirmed the components of the Framework. Conclusions are drawn for subsequent research steps and clinical uses of the Framework.

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Introduction

Understanding the nature of stress and coping in families with a child with a chronic condition[1] is important in that family stress has a potentially negative impact on the child and its effects can be alleviated by nursing interventions. Examples of correlates of high levels of family stress are poorer control among children with diabetes (Auslander, Bubb, Rogge, & Santiago, 1993), poorer growth and pulmonary function among children with cystic fibrosis (Patterson, McCubbin, & Warwick, 1990), and behaviour problems (Shaw & Emery, 1988). Experimental research with such families suggests that some alleviation is possible. It appears that nurses who are able to identify specific stressors and thereby focus their interventions are more effective. It also appears that nursing interventions that focus on current family stressors are more effective than nonspecific approaches to improving family function and child development, child function, and child behaviour (see Burke, Kauffmann, Harrison, & Wiskin, 1995, for a review of this literature). Thus an integral part of nursing practice with these families is a systematic consideration of each family's current, unique stressors and tasks.

Stress and coping concepts are common elements in the theoretical models used in nursing research with families of children with a chronic condition (Burke & Roberts, 1990). In a comprehensive review, Werner (1993) reports that nursing research has taken a wide range of theoretical perspectives on these concepts. This suggests a consensus that stress and coping are critical factors but a lack of consensus on the most appropriate theoretical model of stress and coping. This in turn suggests the need for basic, inductive, qualitative research on the nature of stress and coping, to build knowledge for practice in this area. However, only 4% of the reported stress research by nurses used qualitative methods (Werner).

The purpose of this article is to present a comprehensive, research-based, clinically useable framework of stressors and tasks for these families. Following an overview of the early research steps in the development of the Burke Framework, the clinical uses of the Framework

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[1] Integral to the attempt to describe the range and nature of stressors and tasks for these families is a non-categorical view of chronicity; such a perspective posits that these children and their families have more in common (concerns, stresses, solutions, coping patterns) across diagnoses than they have differences (Perrin et al., 1993).

will be briefly described. Then the final step in the development of the Framework will be presented and discussed in more detail — an analysis of qualitative research to confirm, expand, or discount the components of the Framework. Based on the results of these steps, the Framework will be discussed and conclusions drawn.

Early Stressor Categories and Descriptions

Cohen (1993, p. 93) describes families of a child with a chronic condition as living in a world with "new priorities and unique norms." Terms such as stressors, tasks, challenges, concerns, and problems are commonly used to describe the struggles and triumphs of such families. Early lists and descriptions of stressors were cognitively derived from the clinical experiences of health-care professionals. Others were based on existing theoretical models, such as family development or grieving, and deduced stressors likely to be pertinent to these families (e.g., Erickson, 1976; Zelle & Coyner, 1983). This approach to developing clinically useable tools was followed by the development of questionnaires that included unique stressors for these families.

Early lists of stressors, issues, and challenges, and their closely related coping behaviours for these families, were often compiled as a research instrument was being developed. Typically, items were identified through interviews with professionals, meetings with parents, and literature review. Some of the resulting instruments — for example, the Questionnaire on Resources and Stress (Holroyd, 1987) and the Coping Health Inventory for Parents (McCubbin et al., 1983) — have been used by researchers. Such research instruments have had limited use in nursing practice, perhaps because of the length of time required to administer them, the non-interactive format of the questionnaire, the arbitrary use of non-applicable items, the closed, deductive nature of rating scales, and a perceived lack of personalization.

It is our conclusion that the complex, idiosyncratic, variable nature of stressors for individual families may preclude heavy reliance on structured questionnaires. At the same time, we agree with the non-categorical premise that there are common types of stressful experiences across a wide range of types of families with children with a wide range of types of conditions (Perrin et al., 1993). Our observations are consistent with the assertion that stressors do not occur in a set order and every family does not experience all the stressors. Furthermore, we have observed that at any one time only a few stressors are of concern to a given family.

We deduced that nursing assessment and intervention should focus primarily on the family's *current* stressors. Experimental research findings tend to indicate the effectiveness of a stressor-focused approach to nursing interventions with these families (e.g., Burke, Costello, Handley-Derry, & Kauffmann, 1997; Burke, Kauffmann, Costello, & Dillon, 1991; Magyary & Brandt, 1994; Pless et al., 1994). Nursing interventions directed at the unique, current issues (stressors and tasks) for the parent and child with a chronic condition have better child, parent, and family outcomes than nonspecific or rigidly prescribed interventions. It also appears that stressor-focused nursing interventions delivered during stressful periods for the family have a more positive effect than those delivered in a fixed format at prescribed times.

The Burke Stressors and Tasks Framework builds on earlier stressor research and measurement. It is designed to accommodate our understanding of the nature of stress in these families, as described above. It is customized for our approach to intervention with families of a child with a chronic condition. This approach is grounded in stress-point intervention, developed by Visintainer and Wolfer (1975) for families and children hospitalized with acute, treatable conditions. Our adaptation is Stress Point Interventions for Nurses, or SPIN (see Burke et al., 1995, & Kauffmann, Harrison, Burke, & Wong, in press, for a description). SPIN is anchored in the Burke Stressors Framework (Table 2, column one). Its clinical format can be found in Burke, Kauffmann, Harrison and Wiskin (in press).

Research and Development of the Burke Stressors and Tasks Framework

A research-based, comprehensive description of the nature and range of the stressors and tasks unique to families with a child with a chronic condition is one outcome of our group's research program. We began in 1985 with standard stressful life-event items (e.g., divorce, deaths, moves). The method used a family-oriented, 10-year time frame and allowed for repeated use of the same items. Each family was interviewed again two to three years later. Included were events peculiar to families with a child with a chronic condition (from a list developed by Hymovich, 1988). Exploratory, probing questions were added to refine the list of stressful events. We found intriguing new stressors and dynamics in the parents' answers. (The results for one unique and troubling stressor, repeated hospitalization, are reported in Burke, Handley-Derry, & Costello, 1989.)

In a series of studies following this, we used short, open-ended questions, focus groups, participant observation, and grounded-theory methods with a series of theoretical samples (Burke, Kauffman, Costello, & Dillon, 1991; Burke et al., in press). The Burke Stressors and Tasks Framework for Families with a Child with a Chronic Condition is an outcome of this line of study. Details on the studies within which the Burke Framework was developed are presented elsewhere (Burke et al., in press).

Strategies used in these studies to establish the trustworthiness of the Burke Framework included inter-rater agreement; longitudinal sampling; retrospective and prospective sampling; and replication, triangulation, and saturation (looking for dense descriptions until no new categories emerge). Triangulation strategies (comparisons from more than one perspective) included: triangulation of method by gathering both qualitative and quantitative data; triangulation by source with parent data compared to nurse data, investigator journals, and participant observation; and triangulation by investigators with comparisons between two investigators who independently completed a content analysis of the same data.

All the codes, categories, processes, and descriptors that emerged from the above studies can be subsumed under 11 sets of stressors/tasks in the Burke Framework. In our later samples and analyses no negative cases or new stressors or tasks were found, and density (the completeness of descriptions for categories) was not extended. This supported the conclusion that the Burke Framework was comprehensive.

Clinical Utility

The comprehensiveness of the Burke Framework has been further confirmed by its clinical utility. It has been successfully used in numerous ambulatory and hospital settings (the clinical format can be found in Burke et al., 1995, in press). In the debriefing for one of our feasibility studies (Harrison, Burke, Kauffmann, Doyle, & Handley-Derry, 1990) one nurse reported, "It helped me to formalize my thinking." Another nurse said it "made me look at the picture more closely. I see it as helping me pick up some issues by having it more formalized."

Early results from our recently completed, multi-site, randomized clinical trial support the effectiveness and utility of the Burke Framework and the stress-point approach. On average, in each of the first 22 families observed before, during, and after hospitalization the

nurses identified about 40% of the Burke Framework stressors. However, on average, fewer than half of these stressors were critical or important over the duration (2 to 10 weeks) of the intervention. Across these families every stressor was reported.

Confirmation from Other Qualitative Research Findings

To confirm the research base of the Burke Framework, we employed the grounded theory research strategy of content analysis of reported research results as data. The purpose was to confirm, expand, or discount our findings, which are incorporated in the Burke Framework, against those in the literature (Strauss & Corbin, 1990). The strategy was to distil relevant, qualitative research findings and compare them to our results. Studies of similar phenomena in similar families were used to confirm, discount, or refine the content validity and completeness of the Burke Stressors and Tasks Framework for Families with a Child with a Chronic Condition. Unpublished results were compared separately.

Methods

The method used to review, distil, analyse, and synthesize the findings was adapted from the qualitative "meta-analysis" methods described by Morse and Johnson (1991), Noblit and Hare (1988), and Thorne (1994). Thorne's description used raw data. We adapted the approach for use with qualitative study results. Her discussion of the threats to validity were particularly instructive. Morse and Johnson provided detailed examples in their synthesis of several grounded theories to produce an over-reaching description of similar processes. They appear to have used both raw data and the study results — in their case, the individual grounded theories.

While the well-developed integrative research review methods such as those described by Cooper (1989) were intuitively applicable, the assumptions, processes, strategies, and bases for conclusions are grounded in quantitative research methods. The same applies to measurement validation in which accurate quantification is the objective. Therefore these approaches bore little resemblance to the logic and processes described in the newer qualitative research synthesis approaches. For example, qualitative results are often rich descriptions that lend themselves to further analysis. The end goal in our qualitative research synthesis was comprehensive description rather than measurement. The qualitative conceptual counterparts to the quantitative quality indications of face and content validity are much more highly

valued in qualitative critique. The converse holds for test-retest reliability. In this instance, change over time is expected.

Study Samples and Settings

The qualitative studies reviewed were selected from a 1990–94 CINAHL and Medline search with the following descriptors: child (disabled, chronic disease, terminally ill patients) and family coping or parent or pediatric nursing or nursing intervention or research or parent-child relations.[2] Studies before 1990 were those identified from a previous review of the nursing research on chronically ill and disabled children (Burke & Roberts, 1990). We considered all studies that took a descriptive, inductive approach to the study of concepts related to stressors or within these families. Inclusion and exclusion criteria are noted below.

Some studies described families' stresses in relation to one chronic childhood condition. Some described only one stage, such as diagnosis, or one location, such as a hospital. Most gave the perspective of one family member — usually the mother but occasionally the child, the father, or a sibling. A few described interactions among family members.

Study Selection Procedures

Among the studies initially reviewed, the designs ranged from the content analysis of short-answer, open-ended questions within an essentially quantitative study to grounded theories. Studies using deductive content analysis with a priori themes were included if the categories and codes within the overall themes had been developed using inductive analysis. Only studies that clearly described the subjects were included. Most studies described the setting, while some implied it. The particular qualitative design that was used (e.g., ethnography or grounded theory) was not always clearly specified. Those studies with enough description of method to infer use of a qualitative approach were included. All indicated the data-collection methods

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[2] We are concerned with the "long haul" of having a child with a chronic condition. Therefore we exclude families in the initial crisis of diagnosis or birth and the stages surrounding death that may fit within or require a loss or grieving assessment framework. Conversely, we include families with a child with a life-threatening condition for whom the final stage is not imminent because of the increasingly chronic nature of many of these children's illness trajectories (Perrin et al., 1993)

used. Some earlier studies, usually those published in clinical journals, that did not give details of the analytic procedures used were included.

The selected studies, with abbreviated, relevant research questions, samples, analyses, and results, are shown in Table 1. Most of the studies had other aspects that are not relevant for our purposes.

Analysis Procedures

Each study's relevant findings were extracted. All stressor and task-related results were used as data. The unit of analysis was the researchers' categories and codes; thus quotations from the subjects used as descriptors for categories of data were not used as data unless they had become names of categories. "Bracketing" (consciously ignoring, for the time being) the Burke Framework categories was used so that new stressors or tasks could emerge. Each data segment was then placed beside the Burke category with the best fit. Some data segments logically fit in more than one place. However, given the purpose of confirmation in this analysis, such segments were not repeated in conjunction with more than one of our categories.

Trustworthiness of the Results

Trustworthiness (similar to the quantitative concepts of reliability and validity) of this analysis of findings in the literature was examined using Krefting (1991) and Thorne (1994). Density (ample data to be convincing) is shown within each set. For most studies, there was spread of data across more than one of the Burke categories. Triangulation by source was seen in comparing results from studies of one parent versus studies of both parents and also in comparing results from studies of parents with and without child input. Triangulation by age of study children within and across studies was shown. Triangulation by site of the study (e.g., home, clinic) was established with similar findings across settings. Triangulation across a range of medical diagnostic categories was established. Credibility was enhanced by the inclusion of studies conducted by researchers with many years' experience and related publications about families with children with chronic conditions, specifically Deatrick, Hymovich, Knafl, Robinson, and Snowdon.

Based on these data from qualitative studies, a few refinements were made in the wording of some of the descriptors in the Burke Framework. The refined Framework with supporting data (other qualitative study results) is shown in Table 2.

Table 1 *Qualitative Studies of Family or Parent Stress with a Child with a Chronic Condition*[1]

Investigators, Date, and Relevant Research Question or Purpose	Sample and Setting	Data-Collection Methods	Analysis and Trustworthiness Methods
Allen, Simone, & Wingenbach, 1994 What are your and your family's greatest problems or concerns?	Convenience sample of 14 mothers of ventilator-assisted children discharged home 3 months to 3 years ago; children aged 1 to 16 years	Interview in home	Analysis method not stated, recall bias potential low with no significant differences on a family impact measure
Snowdon, Cameron, & Dunham, 1994 What do families perceive as being the difficult ... aspects of caring for ___?	About 47 mothers and 3 fathers in 50 families with a child with a developmental/cognitive and/or physical disability; children ranged in age from 2 to 37 with a mean age of 12 years; convenience sample of respite care users	Short written answer in mailed survey with 52% return rate	Inductive content analysis and inter-rater reliability
Cohen, 1993 Make analytically explicit how living under conditions of sustained uncertainty becomes part of the lives of families	1. Purposive sample of 33 families with a child with cancer over 5 years; 2. Literature on uncertainty; 3. Purposive sample of parents of 21 children with various chronic or life-threatening conditions; 4. Published accounts of parents	Recorded and transcribed interviews	Grounded theory methods of identifying, developing, relating through theoretical sampling and comparative analysis. Trustworthiness addressed with member checking, peer debriefing, negative case analysis, referenial adequacy and audit trail.
Deatrick, Knafl, & Guyer, 1993 Describe family members' management behaviours	4 families, purposely selected for a range of management behaviours from an earlier sample of 63 families; school-aged child with a chronic condition	Interviews, audiotaped and transcribed	Content analyses with matrix analysis

(cont'd)

Table 1 (cont'd)

Investigators, Date, and Relevant Research Question or Purpose	Sample and Setting	Data-Collection Methods	Analysis and Trustworthiness Methods
Petr & Barney, 1993 What special needs … in raising ___? What serious situations – crises...?	39 parents from 26 families with children with emotional (n = 10), mental/developmental (n = 12), technologically supported children aged 0–21 years; purposively selected from 99 volunteers in programs or disability organizations	4 focus groups with meeting after analysis to confirm results. Tape recorded and transcribed, notes by observer.	Content analysis within predetermined topic areas. Coding reviewed and revised by second researcher. Finding presented to participants to check accuracy.
Barnes, Bandak, & Beardslee, 1990 Identify and classify behaviours	Case studies completed by 186 University of Pittsburgh master's students between 1962 and 1985; infant to adolescent subjects, 74% with chronic or life-threatening conditions	Case study	Fussy logic to identify themes, behavioural data used to expand themes
Deatrick, Knafl, & Walsh, 1988 Describe parent management behaviour	Convenience sample of 12 mothers and 6 fathers of 15 children aged 4 to 21 years, with osteogenesis imperfecta	Interview using open-ended questions at a clinic	Audiotaped, transcribed interviews analysed and 12 families who were "normalizers" were used in the analysis
Young, Creighton, & Sauve, 1988 ...needs of families of infants who were discharged home with oxygen	42 mothers and 2 fathers in 44 families with 48 infants at home on oxygen therapy; average age 21 months (adjusted for prematurity)	Semi-structured interviews in home, hospital, or by phone.	Not stated

Table 1 (cont'd)

Investigators, Date, and Relevant Research Question or Purpose	Sample and Setting	Data-Collection Methods	Analysis and Trustworthiness Methods
Hodges & Parker, 1987 Identify concerns of parents	10 mothers and 4 fathers in 10 families with a school-aged child with diabetes	12 support-group sessions of 1.5 hours each, audiotaped	Listening to tapes and content analysis
Horner, Rawlins, & Giles, 1987 Perceived needs of parents.	164 families. Respondents: 87% mother, 9% father, 4% other; children aged 6 months to 21 years, most 1 to 5 years old	Survey questionnaire	Not stated
a. Robinson, 1987 Parent experiences when their chronically ill child was hospitalized	a. 9 parents of 6 hospitalized children selected as expert witnesses to the phenomenon; children aged 3 months to 21 years with chronic conditions such as muscular dystrophy, meningomyelocele, toxoplasmosis	Intensive, open-ended interviewing, initiated with a semi-structured guide	a. Immediate transcription before conducting another interview; responses guided generation of additional questions; analysis for themes; re-analysed for cross validity and interrelationships
b. Thorne & Robinson, 1988a & b Family members' perspective of health-care relationships when the context is chronic illness	b. Same theoretical sample combined with data from families with an adult with a chronic condition	Fourteen 1½ to 2-hour interviews	b. Phenomenological methods
Canam, 1986 How parents communicate about a child's chronic illness within a family	11 mothers and 3 fathers in 12 families with a child with cystic fibrosis aged 5 to 18 years and a sibling at least 3 years of age	Semi-structured interviews directed by areas of concern from literature, audiotaped, transcribed	Qualitative analysis

(cont'd)

Table 1 (cont'd)

Investigators, Date, and Relevant Research Question or Purpose	Sample and Setting	Data-Collection Methods	Analysis and Trustworthiness Methods
Strauss & Munton, 1985 Identify and understand frustrations..., problems and concerns	16 families in infant stimulation programs with physically disabled, developmentally delayed infants; 10 home and 6 clinic interviews	"Questioned" about sources of support and future worries	Unstated
Hymovich, 1984 How [parents] ... perceive the impact of their child's illness on family developmental tasks? How ... cope in managing...?	63 parents in 38 families with a child with osteogenesis imperfecta, cystic fibrosis, or juvenile diabetes; family home; aged 6 months to 28 years	Interview on critical incidents of satisfying and problematic aspects of living with a chronically ill child; parents interviewed separately and simultaneously; transcribed audiotapes	Content analysis to 100% agreement among three coders. Later instrument development based this study suggests trustworthiness of data
Knox & Hays, 1983 Examine sources of parental stress	33 mothers, 7 fathers, and 1 grandmother in 35 families with a child hospitalized with a long-term disability (n = 11) or cancer (n = 24)	Interviews and re-interviews conducted by authors, audiotaped and transcribed	"Constant, comparative analysis" based on a predetermined model
Venters, 1981 What is the typical course of familial adaptation ... throughout years ...?	96 mothers and 67 fathers in 100 families with 129 children with cystic fibrosis; clinic setting; children under 18 years of age diagnosed at least one year earlier	Questionnaire and semi-structured interview around impacts, responses, and hardships	Unstated

[1]Only study questions, samples, methods and results relevant to this analysis are represented in the table. Most studies had other components, which are not included.

Table 2 ***Qualitative Studies of Stressors Among Parents or Families with a Child with a Chronic Condition: Comparisons with the Stressors and Tasks Framework for Confirmation and Completeness***

Burke Stressors and Tasks	Comparable Stressors, Tasks, Challenges, Issues
Gaining and interpreting knowledge, skills, and experience to manage child's health problem – Amount of help (too much or too little) – Timing of help (too soon or too late) – Conflicting advice or help – Missed or wrong information or help	**Allen, Simone, & Wingenbach** – not knowing about technical issues **Canam** – Too much information at diagnosis and not enough later; remembering information **Cohen** – Limiting and disguising information, extracting, limiting, discounting, transforming, and modifying incoming information **Deatrick, Knafl, & Guyer** – Obtaining, sharing, and controlling needed information **Hodges & Parker** – Knowledge of effects on development **Horner, Rawlins, & Giles** – Health-care providers not listening, not understanding; parent not understanding need for care, not agreeing with treatment; more information on treatments prescribed and available; chances of having another child with the same problem **Hymovich** – Presence or absence of cognitive awareness; understanding child's condition; feelings of inadequacy in performing treatments, preventing complications **Knox & Hayes** – Need to be informed; feeling incapable **Petr & Barney** – Information about services available **Strauss & Munton** – Lack of positive feedback
Acquiring and managing physical resources and services to manage child's health problem (other than child and health care) – Home – School – Child equipment or supplies – Medications – Hassles with people and institutions to obtain the above	**Allen, Simone, & Wingenbach** – Dealing with equipment vendors **Cohen** – Managing physical and social environment to keep child safe **Deatrick, Knafl, & Guyer** – Obtaining health care, help in school **Hodges & Parker** – Purchasing disease-related items; lack of confidence in teachers' ability to manage negative attitudes; lack of school nurses **Hymovich** – Modifying the physical environment; adaptations needed in the home **Petr & Barney** – Special education matched to child's needs, system-induced crises (e.g., a recommendation to move a child out of the home); the system does not work smoothly; advocacy in an unresponsive system **Young, Creighton, & Sauve** – Home setup, equipment, supplies, homemakers

(cont'd)

Table 2 (cont'd)

Burke Stressors and Tasks	Comparable Stressors, Tasks, Challenges, Issues
Acquiring and managing financial resources to care for child's health problem – Direct costs for care of the child – Indirect costs, check if a stress-producing expense, e.g., travel, meals, child care, housing – Hassles within family about how much and what to spend money on – Hassles with people and/or institutions to get financial help	**Allen, Simone, & Wingenbach** – Dealing with insurance companies and government funding agencies, travel to hospital **Deatrick, Knafl, & Guyer** – Obtaining financial resources, equipment, medication, travel to health care **Horner, Rawlins, & Giles** – Help with medical bills **Hymovich** – Financial planning and assistance **Petr & Barney** – Financing uncovered costs **Venters** – Financial strain, debt
Establishing and maintaining effective social support – Extended family – Community – Friends – Parents with similar children	**Cohen** – Changes in social interactions **Deatrick, Knafl, & Guyer** – Participating in support groups; comparing with others; outside sports **Hymovich** – Satisfactions and problems in relationships with extended family members; educating community members; child care by outsiders **Knox & Hayes** – Others with child with same diagnosis having a crisis; emotional support from health-centre staff, family members, and other parents **Petr & Barney** – Emotional support from family, church, and friends important, but unreliable; other parents are best sources of emotional support **Young, Creighton, & Sauve** – Relatives' practical help and emotional support
Rearing a child with a chronic or life-threatening condition – Unmet developmental milestones – Segregation, least restrictive environment, integration issues – Aiding normal development – Modifying development expectations – Preparing for adolescent and adult roles – Behaviour problems – Child care, babysitters – Maintaining development gains outside home, e.g., school, hospital and community	**Allen, Simone, & Wingenbach** – General health **Canam** – Knowing how much and when to tell child about condition and life expectancy **Cohen** – Managing awareness with routines, managing illness with vigilance **Deatrick, Knafl, & Guyer** – Activities of daily living, monitoring diet, treatment, symptoms, activities, devising routines, doing treatments/therapies, showing affection, building coping abilities, participating in decision-making, sharing information, monitoring social activities, finding sitters who are willing and able **Deatrick, Knafl, & Walsh** – Activities of daily living, relationship with child – nurturing, monitoring, disciplining, suitable babysitters **Hodges & Parker** – Special diet regulation, discipline, control tactics, scheduling treatment and medication, lack of child compliance with treatment regimen, child denying condition, eating away from home, child's isolation, irregular school attendance, illness management

Table 2 (cont'd)

Burke Stressors and Tasks	Comparable Stressors, Tasks, Challenges, Issues
Rearing a child with a chronic or life-threatening condition (cont'd)	**Horner, Rawlins, & Giles** – Child care, rest, hygiene, recreation, immunizations and routine health care; child care while working; emergency child care; administration of medications and treatments, sexuality and sex education **Hymovich** – Knowledge of developmental tasks; issues related to self-concept, discipline, peer relationships, and school achievement **Knox & Hayes** – Dealing with child's fears **Petr & Barney** – Child crises, problems and behaviours such as depression, running away, not sleeping, medical problems **Petr & Barney** – Respite breaks **Snowdon, Cameron, & Dunham** – Child's behaviour and isolation **Young, Creighton, & Sauve** – Health, weight gain, interactions as a parent, child's temperament, babysitters, parenting skills
Developing beliefs, values, and philosophy of life incorporating child's health problems and way family copes – Acknowledging feelings and reactions – Trying out new ways of coping – Giving meaning	**Allen, Simone, & Wingenbach** – Feelings about giving up own lives and dreams, anger and frustration **Cohen** – Sustained uncertainty, time tether to present and proximal future, deliberate optimism, viligance **Deatrick, Knafl, & Guyer** – Promoting child's acceptance, conveying impressions to others **Deatrick, Knafl, & Walsh** – Normalization issues **Hodges & Parker** – Dealing with psychological impact on parents (anger, guilt, anxiety, frustration, isolation, over-protectiveness) **Hymovich** – Family attitudes and beliefs; family adjustment – attempting to come to terms with child's condition and its meaning to them; worry about the future; giving time, energy, support, and money to individuals, groups, and organizations related to condition; establish a philosophy of life to cope with the condition; feelings of anger, frustration, guilt, fear, hope, joy, delight, and happiness **Petr & Barney** – Coping with others' attitudes and values that don't see the child "like the child next door" **Strauss & Munton** – Concerns about the future, especially cognitive development, reason to hope, belonging to organizations **Venters** – Endowing meaning to the illness **Young, Creighton, & Sauve** – Changed attitudes towards child (infant); intrapersonal changes – self-confidence and competence versus depression, inadequacy, and loneliness (cont'd)

Table 2 (cont'd)

Burke Stressors and Tasks	Comparable Stressors, Tasks, Challenges, Issues
Management of burden of care for the child – Distribution of tasks and responsibility over family members and health-care system – Conflicts between child, sibling, parent, and family care needs – Shifts in care load – heavier or lighter – Accepting or rejecting need for family sacrifice	**Allen, Simone, & Wingenbach** – Doubts about ability to be responsible for full, constant care **Hymovich** – Resources needed for child care; extra time and energy demands on parents **Knox & Haynes** – Being given too much responsibility for preparation for hospitalization and care in hospital **Petr & Barney** – Inability to provide total care due to other stressful events, daily grind of coping **Snowdon, Cameron, & Dunham** – Caregiving demands **Venters** – Reorganization of daily family activities; sharing the burden of care within and outside the family **Young, Creighton, & Sauve** – Work involved, in-home relief
Identifying and managing sibling issues – Balancing amount of involvement in physical, emotional, and/or financial burdens – Providing an environment for normal development – Helping sibling with philosophical and emotional issues related to child with a health problem	**Allen, Simone, & Wingenbach** – Impacts on siblings **Hodges & Parker** – Sibling problems **Hymovich** – Satisfactions and problems in sibling relationships **Petr & Barney** – Counselling about siblings **Young, Creighton, & Sauve** – Siblings
Maintaining spousal, parental, and nuclear family relationships – Dealing with emotional issues in daily management and coping with small changes in child with health problem – Planning for expected and long-term changes – Maintaining relationships that provide social support – Adjusting to crises related to child with health problem – Satisfaction and dissatisfaction with lifestyle	**Allen, Simone, & Wingenbach** – Effects on family **Deatrick, Knafl, & Guyer** – Balancing time schedules, couple and family activities, obtaining sharing and controlling information within the family **Hodges & Parkers** – Foods (e.g., sweets) for other family members that the child cannot have **Horner, Rawlins, & Giles** – Helping family members get along **Hymovich** – Spouse and parent-child relationships; changes in family lifestyle **Knox & Hayes** – Emotional support from spouse **Petr & Barney** – Marriage counselling **Snowdon, Cameron, & Dunham** – Isolation of the family, family vacations **Strauss & Munton** – Dyssynchronous grieving **Young, Creighton, & Sauve** – Spousal support

Table 2 (cont'd)

Burke Stressors and Tasks	Comparable Stressors, Tasks, Challenges, Issues
Maintaining health of other family members – Managing illnesses of other family members – Exhaustion of primary caregiver (usually the mother)	**Allen, Simone, & Wingenbach** – General health **Hymovich** – Resources of family health, temperament; family member illness and exhaustion **Petr & Barney** – Inability to provide care due to illness, divorce, or death in family **Snowdon, Cameron, & Dunham** – Emotional and mental health relative to day-to-day concerns **Young, Creighton, & Sauve** – level of stress
Maintaining effective relationships with health-care system and other sources of care – Rediagnosis – Changing or conflicting advice in treatment regimens – Changes in physician, clinic, or hospital – Hospitalization – Finding a satisfying role with health-care professionals – Collaboration with team as a parent – Taking advice and/or accepting services – Advocating to change system – Examining and/or using alternative modes of care for child with the health problem	**Allen, Simone, & Wingenbach** – Relations with hospital staff and home-care nurses **Cohen** – Taking control of treatment regimen **Deatrick, Knafl, & Guyer** – Taking responsibility in decision-making, triaging medical care, self-care and specialists **Hodges & Parker** – Support from and trust of health-care providers **Horner, Rawlins, & Giles** – Poor interpersonal treatment, not agreeing with care, difficulty obtaining appointments **Hymovich** – Resources needed for health care; educating health personnel; communicate effectively with health-care professionals **Knox & Hayes** – Professionals with different or unclear expectations **Robinson** – Discrepancies in perceptions between parent and health-care provider on orientation to the child's illness, therapeutic goals, expectations about hospitalization, and perspectives on family involvement **Strauss & Munton** – Circuitous and delayed referrals; negative experiences with health-care personnel; changing pediatricians; seeking non-conventional therapy **Thorne & Robinson** – Working through stages of naive trust, disenchantment and guarded alliance with health-care providers **Young, Creighton, & Sauve** – Deficiencies in practical and emotional resources provided by professionals, duplication, delay, lack of knowledge

Comparison with Unpublished Lists of Stressors

In addition, we are aware of two unpublished, comprehensive lists of family stressors (concerns or tasks) developed by nurse researcher-theorists. These lists were used as additional checks of the completeness of the Burke Framework. Hymovich (1988) presented her list as part of a workshop. This work may have influenced her later instrument-development and theoretical work (Hymovich & Hagopian, 1992). Her list appears to be influenced by her earlier qualitative research (Hymovich, 1984) and later instrument-development results (Hymovich & Baker, 1985). We used this list as a basis for expanding our earliest quantitative data-collection strategies. Hymovich's 13 Situational Tasks and Stressors (Hymovich, 1988) are:

- understand and manage child's condition
- meet needs of all family members
- meet developmental needs of child and siblings
- understand and cope with emotional impact
- help child and siblings to understand and cope
- communicate effectively with health-care professionals and others involved in child's care
- establish and maintain a support system
- establish a philosophy of life to cope with the condition
- manage financial burden
- obtain adequate health care
- adjust organization to accommodate child
- adjust lifestyle
- become an advocate for child

The other unpublished list was developed by Gottlieb (1986) for use with adults and modified by Feeley (1991) for use with children with a chronic condition. Building on the McGill model, the list was used as a coding scheme for nurses' notes about parental health concerns for a randomized clinical trial of a nursing intervention for children with a chronic condition (Pless et al., 1994). Each category has subcategories, and the code book contains definitions and examples of each. The 10 categories of concerns are:

- the chronic illness
- family relationships
- parenting
- child-related issues
- bio-physiological changes
- social system and resources

- environment
- lifestyle and habits
- parent coping
- illness

The Gottlieb/Feeley and Hymovich lists and the Burke Framework contain a similar number (10–12) of stressor categories. Although the researchers were familiar with each other's work, each list was independently developed, and the high degree of conceptual overlap tends to validate the completeness of the lists.

Conclusions from the Analysis of Qualitative Studies

Many diverse situations, types of families, and types of children, and various qualitative methods, have been used to describe crises, tasks, challenges, and stressors in these families. Each single study might have limited transferability (Krefting, 1991), but when the studies are viewed as a group, patterns emerge that fit within the Burke Framework.

There were no stressors or tasks identified in the literature that were not categorizable within the Burke Framework. The fit of the literature to the Burke Stressors and Tasks Framework is shown in Table 2. It seems reasonable to conclude that the Burke Framework is inclusive of the findings within the body of literature reviewed.

With the exception of Hymovich, who strongly influenced our early work, no published study had results that were represented in all of the Burke Framework categories. The next most systematically elaborated results were those of Deatrick, Knafl, and Guyer (1993).

Note that most of the 11 stressor sets have lists of sub-issues (see Table 2, column one). For example, the knowledge and experience stressor/task set has such sub-issues as receiving conflicting advice. Rearing a child with a chronic condition includes probes for segregation and integration issues, child and respite care, and maintaining gains achieved outside the home, such as in hospital or at school. The literature analysis confirms this content with a similar range of issues as those in each stressor's set of sub-issues.

This literature analysis supports the transferability of the Burke Stressors and Tasks Framework to a wide range of types of families with a child with a chronic condition. The same range of diagnostic groups represented in these studies and the similar findings within and across medical diagnostic groups supports the generic view of

chronicity among children living with chronic conditions (more common features than differences among diagnostic groups).

The age ranges of the children in the studies were usually broad, but this was seldom noted as an issue. Although developmental or family-development theory suggests that a developmental trend will emerge, none was found. No one set of stressors was found to chronologically or developmentally follow any other. It appears that issues are not necessarily bound to a particular age group or developmental stage. However, this thesis has not been systematically tested or reported in the literature.

These families' stressors are unique or have idiosyncratic meaning. The stressors and tasks do not neatly fit into developmental and situational stress models. For example, one set of stressors is not necessarily encountered and resolved before another, as family or individual developmental task models would suggest. Situational stress models suggest that experience enhances a person's ability to cope with a stressor on another occasion, but this experiential component, while helpful, does not necessarily decrease the stressfulness of tasks such as repeated hospitalizations or relapses. Instead, experience can enhance the stressfulness of some stressors/tasks to the family.

We concluded that the Burke Framework was inclusive of the stressors and tasks in Hymovich's list. We also concluded that the major categories and almost all of the unpublished Gottlieb/Feeley subcategories were included in the Stressors and Tasks Framework. Exceptions were the bio-physical changes of menopause and aging, which have not emerged in our studies, perhaps because of the ages of the caregivers studied.

Discussion of the Burke Stressors Framework

Although the Burke Framework appears to fit a wide range of types of families, settings, and children with chronic conditions, our studies represent the only tests of its clinical utility to date. However, nurse clinicians and researchers using it have repeatedly noted its relevance and potential utility in work and research with other types of families — specifically, families of an adult with a chronic condition, families of a child living with an imminently life-threatening condition, and families of a child recovering from a serious, possibly handicapping, acute condition or injury. If the Burke Framework is used with families of adults with a chronic condition the addition of stressors appropriate to the older parent ages could be considered. For example, the Gottlieb/

Feeley categories of bio-physical changes of menopause and aging should be considered for inclusion. Nurses in our clinical trial in progress are using it with families of a child with a life-threatening condition who is not in immediate danger. Similarly, the Burke Framework seems to have clinical utility in oncology.

There is some qualitative evidence to support these expert observations that the Burke Framework has broader clinical applicability. Thorne and Robinson (1989) successfully combined data from adult and child family members to develop the guarded-alliance grounded theory. When Morse and Johnson (1991) synthesized several grounded theories of both acute and chronic conditions they found little difference between coping with chronic conditions and coping with acute conditions. They suggest that the professionals' acute-chronic dichotomy may be a false one from the perspective of the client, which leads to the notion that these processes may be unique.

The processes associated with these stressors, as well as the nature of the stressors, appear to be unique. That is, they do not fit neatly into existing theoretical frameworks. Qualitative research is beginning to describe these unique processes. For examples of emerging new theories, see: for hazardous secrets, Burke et al. (1991); uncertainty, Cohen (1993); family management, Deatrick and Knafl (1990); and guarded alliance, Thorne and Robertson (1989). In our own qualitative research and in the studies in the analysis above, we do not see a clear distinction among the processes of stress, appraisal, and coping.

Conclusions

Qualitative research findings, including the research behind the Burke Stressors and Tasks Framework, as a group appear to have comprehensively identified the critical stressors for families with a child with a chronic condition.

The Burke Stressors and Tasks Framework for Families with a Child with a Chronic Condition is clinically tested and research-based and could be used in nursing practice as a cognitive application. Cognitive applications could include enhancing conscious consideration of the range of possible stressors or tasks in family assessments, increasing specificity in the selection of interventions that fit with the types of stressors identified, and giving breadth or conscious focus to evaluations of the effectiveness of nursing interventions with these families.

The next step in the development of nursing knowledge is to form comprehensive descriptions of the processes families use in living with these well-described stresses and in accomplishing their unique tasks.

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Acknowledgements

This article is grounded in research findings from studies funded by the National Health Research Development Program, Queen's University Advisory Research Committee, Ontario Ministry of Community and Social Services, Nursing Department of the Ontario Easter Seal Society, Children's Hospital of Eastern Ontario Research Institute, and Ontario Ministry of Health.

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