

Parents' Perceptions of Chronic Illness Trajectories

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Bien que faisant l'objet de controverses, la notion d'un petit ensemble générique de trajectoires de maladies chroniques se distinguant des diagnostics médicaux spécifiques bénéficie d'un certain appui théorique, clinique et qualitatif dans la sphère de la recherche. L'objectif de cette étude était de décrire, de façon quantitative, les trajectoires parmi les parents d'enfants atteints d'une condition chronique. L'hypothèse a été posée selon laquelle l'analyse factorielle confirmerait la présence de trois trajectoires semblables à celles décrites dans les documents qualitatifs et que les perceptions qu'ont les parents de la trajectoire de leur enfant se distingueraient de façon importante des perceptions médicales. Un total de 140 parents ont fourni des données sur leurs perceptions de l'évolution passée, présente et future de la condition de leur enfant hospitalisé à plusieurs reprises. Quatorze éléments ayant rapport au temps et tirés du questionnaire traitant des ressources et du stress, notamment l'inventaire en matière d'adaptation à l'intention des parents, ainsi que de l'index de stress chez les parents, ont été analysés. Des analyses factorielles de l'expérience pré- et post-hospitalisation ont extrait les mêmes huit éléments pour élaborer trois trajectoires : une situation où la vie est gravement menacée; une situation où l'état se détériore; et une situation stable, positive. Les opinions d'environ un tiers des parents différaient des classifications médicales. Le type de soins infirmiers appliqués n'avait aucune influence sur les perceptions des parents.

The notion of a small, generic set of chronic illness trajectories that can be independent of specific medical diagnoses, though controversial, has some theoretical, clinical, and qualitative research support. The purpose of this study was to quantitatively describe trajectories among parents of children with a chronic condition. It was hypothesized that factor analysis would confirm 3 trajectories similar to those in the qualitative literature and that parents' perceptions of their child's trajectory would differ significantly from medically based perceptions. A total of 140 parents provided data on their perceptions of the past, present, and future course of the condition of their repeatedly hospitalized child. Fourteen time-related items from the Coping Health Inventory for Parents Questionnaire

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on Resources and Stress and the Parenting Stress Index were analyzed. Pre- and post-hospitalization factor analyses extracted the same 8 items to construct 3 trajectories: Life Threatening; Declining; and Stable, Optimistic. The views of approximately one third of the parents differed from medically based classifications. Type of nursing care had no bearing on the perceptions of the parents.

The notion of a small set of illness trajectories among persons with chronic conditions has been suggested as a clinically meaningful alternative to biomedical diagnostic groupings (Rolland, 1987a; White & Lubkin, 1995). The underlying assumption is that psychosocial issues across diverse medical diagnoses have more commonalities than differences (Perrin et al., 1993). Nurses often observe that the perceptions of individuals and their families about the general direction or trajectory of their illness are at variance with the nurse's professional assessment given the particular diagnosis. Qualitative research and theory development, primarily that by Corbin and Strauss (1991), provides some structure to the notion of chronic illness trajectories. The purpose of this paper is to quantitatively describe chronic illness trajectories from the perspective of parents of children with a chronic condition. The parents' perceptions will be contrasted with clinically based nurse perceptions of chronic illness trajectories.

The notion of trajectory from a diagnosis base is described in Rolland's (1987a) typology of chronic illnesses. Rolland utilizes diagnostic groupings and their stages as a mechanism for developing a more psychosocially sensitive classification of chronic illnesses. His typology has two dimensions. The first includes the distinctions of disease characteristics, onset, course, outcome, and degree of incapacitation. Each distinction exists along a continuum. For example, course ranges from progressive to constant to episodic or relapsing; outcome ranges from life-shortening to life-threatening. The second dimension, time, groups diseases with similar characteristics as they follow similar paths over time. Rolland's chronic illness trajectory schema, although not widely used clinically, has been endorsed by the American Academy of Pediatrics as one aspect of its definition of chronic conditions in children (Perrin et al., 1993). In another work, Rolland (1987b) adds a family life cycle as a third dimension. For example, illness that occurs early in life could be "out of phase" and thus more difficult to incorporate into family development.

Although he does not include this in his typology, Rolland (1990) theorizes that families develop their own time lines. Rolland's (1987a, 1987b, 1990) classifications are consistently based in medical diagnosis and do not deal with possible incongruence between the family's conclusions and those of the professionals. Thorne and Robinson (1988),

working at about the same time as Rolland, use the term "trajectory projection," noting that nurse, physician, affected individual, and family members all have their own perspectives on the course of a given illness and that these can diverge greatly from the general characteristics of the disease and the symptoms that usually accompany it.

Corbin and Strauss (1991), starting from the individual's perceptions rather than from the diagnosis and related stages, assert that the individual's and family's view of the trajectory is fundamental to the person's understanding and the concept of chronicity. Their trajectory framework includes eight phases, each of which can have the sub-phases of reversal, plateau, upward movement, or drop. Miller (1993) and Smeltzer (1993) apply the Corbin and Strauss framework to persons with multiple sclerosis. Robinson et al. (1993) have developed protocols for elderly persons based on trajectory phases. In contrast, Wiener and Dodd (1993) conclude that cancer trajectories are different from chronic trajectories because they are life-threatening.

Critiques of the Corbin and Strauss (1991) view of trajectory range from fundamental to the need for further development. Cooley (1999) analyzes and evaluates trajectory (Corbin, 1999) as a mid-range nursing theory in need of further theoretical work on internal consistency and parsimony. Silva (1999), responding to Cooley's evaluation, concludes that such highly conceptual endeavours tend to favour the educational elite and seem remote from the everyday experience of nurses and their clients.

The view in this paper is of chronic illness trajectory as one construct of many that may be relevant to nursing those with chronic conditions and their families. As used here, *trajectory* refers to the construct of chronic illness trajectory.

The schemata of Rolland and Corbin and Strauss (1991), though developed from different perspectives, have some similarities. The primary source of data for classification in Rolland's schema is health-care professionals. The primary source for Corbin and Strauss is the family or the person with the chronic condition. Both schemata are attempts to integrate the psychosocial and biophysiological aspects of chronicity. Notably, the resulting categories have similarities — for example, life-threatening (Rolland) and dying (Corbin & Strauss). On closer examination the two schemata also exhibit important differences. In contrast to Rolland's (1987a, 1987b, 1990) logically derived theoretical schema, Corbin and Strauss's phases are data-based, evolving from grounded theory research.

Burke (1997) discusses the nursing practice and research implications of the chronic illness trajectory construct. She notes that experienced practitioners generally recognize and clinically use the notion of trajectory with their clients, and discusses the need for further description. Miller's (1993) evaluation of Corbin and Strauss's (1991) framework notes the need for further research. Cooley (1999), however, views quantitative research, presumably with experimental designs, based on the chronic illness trajectory theory as premature. However, there is a need for quantitative descriptions of the trajectory construct to extend the existing qualitative descriptions.

This paper presents a secondary analysis of quantitative data on illness trajectories from a study on the effectiveness of an educational, supportive nursing intervention for families of repeatedly hospitalized children with a chronic condition (Burke, Harrison, Kauffmann, & Wong, *in press*; Kauffmann, Harrison, Burke, & Wong, 1998). Interviewers reported that some parents showed anxiety when answering some questions. For example, "I worry about how our family will adjust after ___ is no longer with us" (Holroyd, 1987). This comment suggests a life-threatening illness trajectory within a study population intended to comprise children with a chronic rather than immediately life-threatening condition.

Upon reflection — and using our clinical knowledge of the study population — we concluded that, from the perspective of the parents in the sample, there would be three possible trajectories. These were labelled: (a) slowly declining, (b) life-shortening, and (c) life-threatening. Upon examination of Corbin and Strauss's (1991) trajectory phasing, we concluded that three of the eight phases were very close to what parents in the sample might expect: (a) stable — "illness course/symptoms controlled by regimen"; (b) downward — "progressive deterioration in physical/mental status characterized by increasing disability/symptoms"; and (c) dying phase (p. 163).

Clinical experience suggested that the parents were not guided in their view of their child's illness trajectory by medical diagnosis alone. They often held views about the likely outcome that were not in agreement with those of the child's professional caregivers. If this were the case, medically based trajectories would often differ from those of parents.

Corbin and Strauss (1991) view chronic illness trajectory as the central phenomenon in a mid-range theory that can guide nursing care, thereby shaping the client's perceptions about the trajectory. In this

view, parents of children receiving extensive interventions by experienced nurses would have trajectories somewhat different from parents in similar situations but with less nurse contact.

Independent of the effects of nursing interventions, a parent's view of the illness trajectory might be expected to change somewhat over the course of the child's hospitalization due to clinical changes. For example, the child's physical health is apt to change in response to hospitalization and treatments that might be more or less successful in the eyes of the parent. It would be consistent with the trajectory construct if the views of some parents concerning the relative degree of life threat, or the relative stability of their child's condition, were to change over the course of the study. Nevertheless, the individual changes should not affect the range of trajectory types for the group overall.

The purpose of this study was to test theory about the chronic illness trajectory. According to the qualitative literature, within a group of parents the existence and structure of perceptions about the children's chronic illness trajectories will be stable over time, despite shifts in individual perceptions of a child's trajectory. For example, most of the parents will have a cognitive understanding of the trajectory as life-threatening, whether an individual parent views their child as very life-threatened or not life-threatened at all. Therefore, despite changes in the perceived degree of life threat or relative stability of the child's condition, the existence and structure of illness trajectories across parents will have remained unchanged from the time they entered the study to 3 months after discharge.

Therefore, the hypotheses were that, from the perspective of the parents, the chronic illness trajectory of a repeatedly hospitalized child will:

- (a) contain three unique trajectories — life-threatening, life-shortening, and slowly declining
- (b) differ significantly from diagnosis-based trajectories generated from medical diagnoses and surgical procedures
- (c) differ significantly between those with extensive, experienced nursing care and those with usual care
- (d) change after hospitalization for a significant number of *individual parents*
- (e) be similar in number and structure before and after a hospitalization for *parents as a group*.

Methods

Confirmatory factor analyses were conducted to test the hypotheses about trajectories from the perspective of parents of children with chronic conditions (Polit, 1996; Tabachnick & Fidell, 1996). Chi-squared analysis was used to test for changes in individual parents' views of their child's illness trajectory over time and to test for differences between trajectories developed from parent data and trajectories developed from medical data.

Table 1 *Child and Family Socioeconomic and Hospitalization Backgrounds*

	<i>N</i>	Mean	<i>SD</i>	Minimum	Maximum
Child Characteristics					
Age (in years)	115	7.1	3.8	1	16
Developmental age (in years) before hospitalization ^a	114	5.6	4.2	3 months	17
Number of prior hospitalizations during lifetime	112	8.9	11.0	1	100
Number of weeks hospitalized during lifetime	112	13.3	18.9	<1	155
Family Characteristics					
Study parent's ^b years of education	115	13.6	2.4	8	19
Parent's approximate yearly family income (US \$)	110	33,000	23,700	3,200	158,000
Number of children at home	115	2.3	1.0	1	7
Number of adults in home	114	1.9	.52	1	4
Number of adults involved in daily care of study child	114	2.1	.76	1	4
^a Measured using Scales of Independent Behavior (Bruininks, Woodcock, Weatherman, & Hill, 1985)					
^b Study parent was usually the mother					
^c One very high income outlier deleted					

Sample

The 140 children in the study had a chronic condition and were in no immediate danger of dying from their health problems. They had all been hospitalized in the past and were expected to require hospitalization again in the future. A total of 115 were hospitalized over the study period. All of the children except those from oncology clinics had had their condition for more than 1 year. The children from oncology clinics were not in the early stages of treatment and were expected to survive.

Sociodemographic and hospitalization histories of the children and families are shown in Table 1. The children had severe health problems. Primary diagnoses, in descending order of frequency, were: cerebral palsy, spina bifida, congenital genitourinary defects, cancer (responding to treatment), chronic renal disease, cystic fibrosis, congenital hip defects, other orthopedic conditions (e.g., osteogenesis imperfecta, scoliosis), cardiac defects, gastrointestinal conditions, muscular dystrophy, cleft palate, diabetes, and epilepsy. As can be seen in Table 1, many had developmental delays. Many of these children had multiple handicaps. Approximately one third had learning problems and/or mental health problems. Many had visible handicaps requiring a wheelchair (27%), prescribed footwear (16%), other type of brace (13%), and/or a hearing aid (4%).

The children and their families were recruited by 23 ambulatory-clinic nurses in three moderate-sized to large cities. As part of the study, they had been randomly assigned to receive a nurse-delivered support intervention for hospital stresses or usual care (Stress Point Intervention by Nurses [SPIN] — Kauffmann, Harrison, Burke, & Wong, 1998).

Instruments

Parent perceptions of trajectory. On the assumption that trajectory implied direction over time, three parent questionnaires were scanned for items that could be viewed as having a time-spanning orientation, past to present or present into the future, in relation to the child with a chronic condition. The Coping Health Inventory for Parents (CHIP — McCubbin et al., 1983), the child scales of the Parent Stress Index (PSI — Abidin, 1986), and the Questionnaire on Resources and Stress (QRS — Holroyd, 1987; 38 items of the 66-item short form selected a priori as not overlapping conceptually with PSI items) were examined for potential chronic illness trajectory items. Each instrument has several scales. The 14 potential trajectory items are shown in Table 2.

Table 2 *Time-Spanning Items about Child with a Chronic Condition in CHIP, QRS, and PSI*

		In Final Factor Analysis Solutions
Coping Health Inventory for Parents		
Item no.	Item	
CHIP1	Believing that my child will get better	Yes
CHIP4	Believing that things will always work out	Yes
CHIP19	Encouraging my child with a disability to be more independent	No
Questionnaire on Resources and Stress		
Item no.	Item	
QRS5	I don't worry too much about ___'s health	No
QRS12	As time passes I think that it will take more and more time to care for ___	No
QRS14	It bothers me that ___ will always be this way	No
QRS18	I worry that ___ senses that he/she does not have long to live	Yes
QRS26	I worry about how our family will adjust after ___ is no longer with us	Yes
QRS28	I worry about what will be done with ___ when he/she gets older	No
QRS31	In the future ___ will be more able to help himself/herself	No
QRS33	___ cannot get any better	Yes
Parenting Stress Index		
Item no.	Item	
PSI22	In some areas my child seems to have forgotten past learning & gone back to doing things characteristic of younger children	Yes
PSI45	My child has more health problems than I expected	Yes
PSI47	My child has turned out to be more of a problem than I expected	Yes

Medical diagnosis-based trajectories. Using medical diagnostic data alone, each child was assigned to a life-threatening or chronic illness trajectory. There was sufficient detail available to use Rolland's (1987a) approach, but only enough to allow classification into two categories — chronic or life-threatening. Data used were discharge diagnosis, surgical and/or medical procedures, originating clinic, and parent report of the child's medical diagnosis. For example, a child with muscular dystrophy hospitalized for a tracheostomy was classified as being on a life-threatened trajectory; a child with cerebral palsy admitted for heel-cord lengthening was classified as being on a chronic trajectory. The classifications were done independently by three of the investigators and resulted in 100% agreement. See LaSalle (1997) for details.

Data-Collection Protocol

Parent ratings on the CHIP, PSI, and QRS were obtained by a research assistant about 2 weeks before an expected hospitalization (T1). Interviews took place in a private room at a clinic or in the parent's home. For those parents whose child was actually hospitalized, sociodemographic and family data were collected in a telephone interview about 10 days after discharge. Charts were reviewed to obtain diagnostic and hospitalization data. A second in-person interview took place 3 months after discharge (T2), at which time the CHIP, PSI, and QRS were again used.

Results

Potential Chronic Illness Trajectory Items

Three (7%) of the 45 CHIP items fit the selection criteria. All selected CHIP items were from the Family Coping factor (maintaining family integration, cooperation, and optimistic definition of the situation). No time-related items were identified in the Parents' Personal Coping factor or Health Care Communication Coping factor.

Of the 38 QRS items used in the study, eight (21%) fit the selection criteria. The time-related items from the QRS fell in the Life Span Care and Terminal Illness Care scales. None were found in the Personal Burden, Preference for Institutional Care, Lack of Personal Reward, or Limits on Family Opportunities scales.

Three (6%) of the 47 child PSI items fit the selection criteria. The PSI items were from the Child Demandingness and Child Acceptability scales. No items that fit the selection criteria were found in the Child

Adaptability, Mood, Distractibility and Hyperactivity, or Reinforcing Parent Scales.

Illness Trajectory Confirmatory Factor Analyses

A correlation matrix showed that all 14 questions had modest, significant correlations with many of the other items. An initial principal-components extraction with varimax rotation was performed using SPSS for Windows on these 14 items at T1. Seven subjects with missing data were deleted in the principal component analysis. No outliers were identified. Four factors were shown in the initial solution, but one factor had only one variable. With the objective of maximizing the variance accounted for, items that loaded on any single component at .20 or less, or loaded between .20 and .30 approximately equally on two or more factors, were deleted. Eight variables remained, which loaded on three components.

Next, a maximum-likelihood factor analysis was conducted with a varimax rotation. This yielded three factors with cut-off eigenvalues of 1.0 or more. Theoretically, an oblique rotation would be likely among illness trajectories. A maximum likelihood factor analysis was conducted using a direct oblimin rotation that showed the eight items grouped within similar factors with similar factor loadings, as in the varimax rotation. As orthogonal rotations are more directly interpretable, these were used in further analysis (Table 3).

Factor naming was carried out by examining the content of the items loading on the factor. The factors were named Life Threatening Illness Trajectory; Declining Illness Trajectory; and Stable, Optimistic Trajectory. The T1 factor analysis explained 59% of the variance among the items.

Illness Trajectories 3 Months Later

There was stability of the trajectory factors within the parents as a group over time. Of the 140 children entered into the study, 115 were hospitalized and therefore continued to T2. T2 data from the PSI, QRS, and CHIP were available for 113 of these children. Factor analysis was done on the T2 data using the same procedures as those described above for the T1 data. There was a three-factor solution at T2. The T2 factor analysis was very similar in structure to the one obtained from the T1 data. The order in which items in the T2 factors were extracted varied slightly. Only one question changed factors. "Cannot get any better" (QRS33) loaded negatively (-.43) on the stable, optimistic factor at T1 and positively on the life-threatening factor at T2 (.64) (see Table 3). The T2 factor analysis explained 62% of the variance among the items.

Table 3 *Factor Loadings, Communalities (h²), Eigenvalues, and Percentages of Variance for Illness Trajectories from Parent's Perspective at Times 1 and 2*

Factor Loadings									
Factors and Questions	Item Source	Time 1 (N = 140)				Time 2 (N = 111)			
		F1	F2	F3	Communality	F1	F2	F3	Communality
Life Threatening Illness Trajectory Factor (Factor 1 at T1, Factor 2 at T2)									
I worry about how our family will adjust after ____ is no longer with us	QRS26	<u>.98</u>	-.14	-.09	.99	-.08	<u>.55</u>	-.14	.32
I worry that ____ senses that he/she does not have long to live	QRS18	<u>.35</u>	-.05	-.14	.14	-.31	<u>.64</u>	-.06	.42
____ cannot get any better (item repeated below)	QRS33	Loaded negatively on stable, optimistic factor below				-.31	<u>.60</u>	-.01	.46
Declining Illness Trajectory Factor (Factor 2 at T1, Factor 3 at T2)									
My child has turned out to be more of a problem than I expected	PS147	.04	<u>.06</u>	.16	.92	.16	-.22	<u>.63</u>	.46
In some areas my child seems to have forgotten past learning and gone back to doing things characteristic of younger children	PS122	-.23	<u>.45</u>	.03	.26	.20	-.00	<u>.39</u>	.19
My child has more health problems than I expected	PS145	-.04	<u>.34</u>	.03	.12	-.06	-.04	<u>.55</u>	.30
Stable, Optimistic Illness Trajectory Factor (Factor 3 at T1, Factor 1 at T2)									
Believing that my child will get better	CHIP1	-.08	.02	<u>.83</u>	.70	<u>.96</u>	<u>-.28</u>	<u>.02</u>	<u>.42</u>
____ cannot get any better (item repeated above)	QRS33	.37	.08	<u>-.42</u>	.33	Loaded positively on life-threatening factor above			
Believing that things will always work out	CHIP4	-.09	.08	<u>.37</u>	.15	<u>.41</u>	<u>-.13</u>	.18	.22
Eigenvalues		2.24	1.41	1.11		2.50	1.36	1.09	
Percentage of Explained Variance by Each Factor		28.0	17.6	13.8		31.2	17.0	13.6	
Percentage of Explained Variance for Each Factor Analysis					59.4				61.8

Difference Between the Trajectories of Intervention and Usual Care Parents

T-tests showed no significant difference between the intervention group and the usual care group on illness trajectory factor loading scores at T1, thus allowing testing for significant difference between types of nursing care at T2. No significant differences were found in trajectories at T2. Therefore the sample was treated as one group in the subsequent analyses.

Changes Over Time in Parent's Perception of Child's Placement on Illness Trajectory

Despite stability of trajectory factors within the parental group over time, there was significant change in the trajectory of the individual parent in the 3 or 4 months between T1 and T2 ($\chi^2(4) = 38.45; p < .001$), with 43% of parents having a different perception of their child's dominant trajectory 3 months after discharge from hospital (see Table 4).

At the outset, when the children were expected to be hospitalized, the most common trajectory was declining (45/113), followed by life-threatening (39/113), and the least common was stable, optimistic (29/113). At 3 or 4 months after discharge, the most common trajectory was stable, optimistic (54/113), with declining still in the middle (35/113) and life-threatening the least common (24/113).

Those parents who perceived their child as on a life-threatening trajectory before hospitalization were the most apt to have changed their view 3 months after discharge. More than half of this group had altered their view, with most of these (13/39) seeing their child as on a stable, optimistic course, and fewer (8/39) seeing their child as on a declining, less immediately life-threatening trajectory. Just under half of this group of parents (18/39) continued to view the dominant illness trajectory for their child as life-threatening.

Similarly, of those parents who initially perceived their child as on a declining trajectory, about half held the same view 3 months after discharge. Of the half who had a different perception 3 months after discharge, most (18/45) had altered their view to a stable, optimistic trajectory. A few (3/45) had changed to a view that their child was on a life-threatening trajectory.

In contrast, several parents who initially viewed their child as on a stable, optimistic trajectory had changed their perception 3 months after

Table 4 *Changes in Dominant Trajectory Before and After Hospitalization*

Three Months after Discharge — T2	Number of Parents Before Hospitalization — T1			Totals at T2 by trajectory
	<i>Life-threatening</i>	<i>Declining</i>	<i>Stable, optimistic</i>	
Life-threatening	18	3	3	24
Declining	8	24	3	35
Stable, optimistic	13	18	23	54
Totals at T1 by trajectory	39	45	29	113
% Within same trajectory at both T1 and T2	15.9%	21.2%	20.4%	57.5%
% Changed from T1 to T2	18.6%	18.6%	5.4%	42.6%
% Agreement within the same trajectory at both T1 and T2	46.2%	53.3%	79.3%	

discharge (6/29), with half of these changing to a life-threatening trajectory and the other half to a declining illness trajectory.

Differences Between Parent-Based and Medically Based Classifications

The hypothesis that there would be a significant difference between illness trajectories based on parent data and those based on medical data was not proved. The observed frequencies in each cell were not significantly different from those expected as tested with chi square. However, more than twice as many parents (35%) than medical data alone would suggest (15%) thought that their child was life-threatened (Table 5). Overall there was only 63% (6% + 57%) agreement between illness trajectories based on parent data and those based on medical data. For more than one third of the time, therefore, parents and professionals might not hold the same view of the direction or course of a child's illness. Note that in the real world professionals have more historical, biomedical, and current status information than was used here to categorize.

Table 5 *Trajectory Classifications Based on Parent Data Versus Medical Data*

Based on Medical Data	Based on Parent Data		
	<i>Life-threatening</i>	<i>Chronic</i>	<i>Medical totals by trajectory</i>
Life-threatening	<i>n</i> = 7 6% agreement	<i>n</i> = 10 9% disagreement	<i>n</i> = 17 15% life-threatening
Chronic	<i>n</i> = 32 28% disagreement	<i>n</i> = 64 57% agreement	<i>n</i> = 96 85% chronic
Parent totals by trajectory % of total	<i>n</i> = 39 35% life-threatening	<i>n</i> = 74 67% chronic	<i>N</i> = 113 100% of those hospitalized having complete parent data

Discussion

Substantial support for a chronic illness trajectory construct is provided by the findings from the perspectives of parents with children with chronic conditions. The three expected trajectories emerged from the confirmatory factor analyses. Furthermore, the number and structure of the trajectories remained essentially the same over time despite the movement of individual parents from one trajectory to another. The findings demonstrate, for the first time, the ability to measure trajectories with questionnaire data.

A parent's perception of their child's trajectory often changes after a hospitalization. Those who initially saw their child as life threatened or declining were the most apt to change their ratings. Conversely, parents who were optimistic seldom changed their view.

It is interesting that time-spanning items that suggest trajectories were found in all three parent questionnaires selected for use in a study of families with children with chronic conditions. It is also of note that while the items tended to cluster in one or two of the questionnaires' scales or factors that had been statistically or theoretically constructed, none had an expressly identified trajectory construct. This tends to support the notion of trajectory as a dimension but not as a central organizing construct for parents of a child with a chronic condition. This study's factors and the names given to them are very different from the content of the scales on the questionnaires from which they were selected. This might suggest that the trajectory construct is a part of parent coping, parenting stress, and the caregiving stress and resources tapped in the questionnaires. Nevertheless, the trajectory con-

struct was implicit and cut across these broad areas of concern to the chronicity researchers who developed the questionnaires used in the study. These questionnaires and the findings of this study echo Hayes's (1997) conclusion that the parent-related literature does not provide a cohesive theory within which to understand parent responses to chronicity.

However, the notion that parental perceptions about the course of the illness can be affected by experienced nurses devoting more time to families, such as the Corbin and Strauss (1991) view that nurses "can affect the choices made about illness management and ultimately have consequences for the direction taken by the illness course" (p. 156), was not supported. The period of time the parents were studied in this investigation was short, however, in the context of the duration of their child's illness. Generalization is also limited by the post-hoc design and possible lack of breadth in measurement of the trajectory construct.

It may be premature for nurses to develop interventions based on parents' perceptions of their child's illness trajectory, as Robinson et al. (1993) have developed for elderly persons. If nurses take parents' perceptions of their child's chronic illness trajectory into consideration as one factor in their care, as they say they do, then these results strongly suggest that these perceptions should be reassessed over time, since they are apt to change.

While the perceptions of parents were not statistically different from those based on medical data, an argument can be made that lack of agreement among more than a third of the parents is clinically sufficient to merit careful assessment of professional assumptions concerning their ideas about their child's illness trajectory. For example, parents and professionals are not likely to work well together if one is thinking treatment and the other is thinking palliative care.

There are limitations related to the study being a secondary analysis of data collected for another purpose. First, the sample does not cover the entire range of trajectory phases; for example, only three of the eight Corbin and Strauss (1991) trajectory phases were expected in this sample. Second, the views of only one family member were examined — those of the child's primary caregiver, who was usually the mother. Paternal, sibling, and study-child perspectives could be different. Third, only a few questions involved the time dimension required to study trajectories. It is very probable that more questions are needed, as the variance accounted for by the factor analysis was moderate.

These findings support the notion that some parents view their child's cancer as having a trajectory somewhat similar to that of a chronic condition. Wiener and Dodd (1993) found that, among adults, life-threatening cancer trajectories were different from chronic illness trajectories, whereas the present study did not find such a distinction. Although many parents of children with cancer saw their child as having a life-threatening illness trajectory, many others did not. Furthermore, over half of the parents who viewed their child as having a life-threatening trajectory switched to a predominately optimistic, stable trajectory or less, often a declining trajectory, following hospitalization and recovery.

The next research step is to develop a clear, theoretical description of the construct of trajectory upon which reliable, valid assessment tools can be developed. Concurrently, nurse perceptions of their clients' illness trajectories need to be described. The assumption that a good fit — or at least a mutual understanding — between client and professional, leading to more effective nursing interventions, can then be tested. Also, the assumption that trajectory-specific interventions are more effective than diagnosis-specific ones should be tested as such interventions are developed. It will be fascinating to see the variations in perceptions of chronic illness trajectory held by different members of a client's family. And finally, if the trajectory construct is valid for chronicity, and acuity is different from chronicity, is the trajectory construct valid for acuity as well?

The next clinical steps are to consider eliciting parents' views on the course of their child's illness, as these may not concur with the assumptions of nurses. The findings of this study indicate that the views of parents should be reassessed from time to time, particularly after significant events such as hospitalization. Based on other research on stressful events for these families, rediagnosis, change of treatment plan, change in health-care professionals, and change in child's condition would also be points at which parents' perceptions of illness trajectory should be reassessed.

Conclusions

A factor analysis of the perspectives of parents of children with a chronic condition confirmed the existence of three chronic illness trajectories. These trajectories were: life-threatening; declining; and stable, optimistic. Although there were significant changes within individual parents over time, the structure of the three trajectories remained stable. Differences in nursing interventions were not related to trajectories.

Medical classifications of illness as life-threatening (e.g., cancer) versus chronic (e.g., cerebral palsy) appear to have a loose relationship with parent perceptions, but the views of many parents differed from what the medical diagnosis would suggest as the most likely course of the illness.

References

- Abidin, R.R. (1986). *Parenting Stress Index*. Charlottesville, VA: Pediatric Psychology Press.
- Bruininks, R.H., Woodcock, R.W., Weatherman, R.F., & Hill, B.K. (1985). *Development and standardization of the scales of independent behavior*. Allen, TX: DLM Teaching Resources.
- Burke, S.O. (1997). Trajectories and transferability: Building nursing knowledge about chronicity. *Canadian Journal of Nursing Research*, 28(4), 3-7.
- Burke, S.O., Harrison, M.B., Kauffmann, E., & Wong, C. (In press). Family effects of a nursing intervention for parents of repeatedly hospitalized children with chronic conditions. *Journal of Family Nursing*.
- Cooley, M.E. (1999). Analysis and evaluation of the trajectory theory of chronic illness management. *Scholarly Inquiry for Nursing Practice: An International Journal*, 13, 75-95.
- Corbin, J. (1999). Response to "analysis and evaluation of the trajectory theory of chronic illness management." *Scholarly Inquiry for Nursing Practice: An International Journal*, 13, 105-109.
- Corbin, J.M., & Strauss, A. (1991). A nursing model for chronic illness management based upon the trajectory framework. *Scholarly Inquiry for Nursing Practice: An International Journal*, 5, 155-174.
- Hayes, V.E. (1997). Families and children's chronic conditions: Knowledge development and methodological considerations. *Scholarly Inquiry for Nursing Practice: An International Journal*, 11, 259-290.
- Holroyd, J. (1987). *Questionnaire on resources and stress for families with chronically ill or handicapped members*. Brandon, VT: Clinical Psychology Publishing.
- Kauffmann, E., Harrison, M.B., Burke, S.O., & Wong, C. (1998). Family matters: Stress-point intervention for parents of children hospitalized with chronic conditions. *Pediatric Nursing*, 24, 362-366.
- LaSalle, J. (1997). *Developmental reactions to repeated hospitalization within life-threatening and chronic illness trajectory frameworks*. Unpublished master's thesis, Queen's University, Kingston, Ontario.
- McCubbin, H.I., McCubbin, M.A., Patterson, J.M., Cauble, A.E., Wilson, L.R., & Warwick, W. (1983). CHIP - Coping Health Inventory for Parents: An assessment of parental coping patterns in the care of the chronically ill child. *Journal of Marriage and the Family*, 45, 359-370.
- Miller, C.M. (1993). Trajectory and empowerment theory applied to care of patients with multiple sclerosis. *Journal of Neuroscience Nursing*, 25, 343-348.

- Perrin, E.C., Newacheck, P., Pless, I.B., Drotar, D., Gortmaker, S.L., Leventhal, J., Perrin, J.M., Stein, R.E.K., Walker, D.K., & Weitzman, M. (1993). Issues involved in the definition and classification of chronic health conditions. *Pediatrics*, 91, 787-793.
- Polit, D.F. (1996). *Data analysis and statistics for nursing research*. Stamford, CT: Appleton & Lange.
- Robinson, L.A., Beril, C., Arcangelo, V., Reitsnysder, J., Rothman, N., & Smeltzer, S. (1993). Operationalizing the Corbin & Strauss trajectory model for elderly clients with chronic illness. Including commentary by Corbin JM. *Scholarly Inquiry for Nursing Practice*, 7(4), 253-268.
- Rolland, J.S. (1987a). Chronic illness and the family: An overview. In L.M. Wright & M. Leahey (Eds.), *Families and chronic illness* (pp. 33-54). Springhouse, PA: Springhouse.
- Rolland, J.S. (1987b). Chronic illness and the life cycle: A conceptual framework. *Family Process*, 29, 203-221.
- Rolland, J.S. (1990). Anticipatory loss: A family systems developmental framework. *Family Process*, 29, 229-224.
- Silva, M.C. (1999). Response to "analysis and evaluation of the trajectory theory of chronic illness management." *Scholarly Inquiry for Nursing Practice: An International Journal*, 13, 97-103.
- Smeltzer, S.C. (1993). Use of the trajectory model of nursing in multiple sclerosis. *Scholarly Inquiry for Nursing Practice: An International Journal*, 5, 219-234.
- Tabachnick, B.G., & Fidell, L.S. (1996). *Using multivariate statistics*. New York: HarperCollins College.
- Thorne, S.E., & Robinson, C.A. (1988). Health care relationships: The chronic illness perspective. *Research in Nursing and Health*, 11, 293-300.
- White, N., & Lubkin, I.M. (1995). Illness trajectory. In I.M. Lubkin (Ed.), *Chronic illness: Impacts and interventions* (pp. 51-73). Boston: Jones & Bartlett.
- Wiener, S.L., & Dodd, M.J. (1993). Coping and uncertainty: An illness trajectory perspective. *Scholarly Inquiry for Nursing Practice: An International Journal*, 7, 17-31.

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