Chronic illness and the family life-cycle

Nancy M Newby PhD(e) RN
Nurse Manager, Medical Divisions, Christian Hospital Northeast, St Louis, Missouri, USA

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Chronic illness is currently the outstanding health issue in the United States. It creates increased family stress, requires constant adaptation by the family members and poses a challenge to nurses to better understand and meet the needs of the family as well as the individual. This paper presents a psychosocial typology of chronic illness and discusses the importance of time phasing of the chronic illness. A conceptual framework for analysing the interaction of chronic illness with family and individual life-cycles is outlined. Knowledge of life-cycle stressors is essential for nurses to better delineate the relationship between the vertical and horizontal life stressors which affect the family system.

INTRODUCTION
Chronic illness is currently the outstanding health problem in the United States of America (Larkin 1987) Lambert & Lambert (1987) reported that approximately 110 million people within the United States are presently afflicted with one or more chronic illnesses. Of the persons affected, nearly 32.4 million are significantly limited in their daily activities as a result of their disease (Lubkin 1986). The purpose of this paper is to present a psychosocial typology of illness and to discuss the time phasing of illness, to provide a comprehensive view of chronic illness. Family systems theory and the family life-cycle perspective are used as frameworks to study how families adapt to chronic illness in order to improve nursing care. Wright & Leahy (1984) stated that nurses can assist families in adapting to chronic illness and can provide essential support to the family system.

Miller (1992) defined chronic illness as a permanently altered health state, caused by a non-reversible pathological condition, which leaves residual disability which cannot be corrected by a simple surgical procedure or cured by a short course of medical therapy. Although chronic illness has a profound effect upon the individual, an immense responsibility is simultaneously imposed upon the family (Shaw & Halliday 1992). Recent changes in the financing of health care have resulted in an escalation of reliance on families for long-term care. In many instances, families assume the role of care provider for extended periods of the family life-cycle. The family unit in our modern society must be dynamic and evolutionary, to maintain stability and to manage the stresses of both normal transition phases and crises which are out of the ordinary, such as chronic illness.

Family responses to chronic illness vary according to the age and the developmental stage of the ill individual, the strength and coping mechanisms of family, and the family life-cycle stage. To place the unfolding of chronic illness into a developmental context, it is crucial to examine the intertwining of three evolutionary threads—the illness, the individual, and the family life-cycle (Rolland 1987).

PSYCHOSOCIAL TYPOLOGY OF CHRONIC ILLNESS
It is important to link the client's and the family's psychosocial dimensions into the chronic illness typology. This scheme is very beneficial for nurses because it helps to define and classify the illness and to clarify the relationship between the illness and family life. The typology conceptualizes broad distinctions of onset, course, outcome expected, and the degree of incapacitation experienced by
the individual who is chronically ill. The typology also identifies related family stresses (see Figure 1).

Onset

Illnesses can be divided into those which have an acute onset, such as a stroke or myocardial infarction, and those with a gradual onset, such as arthritis or Alzheimer’s disease. Diseases with a gradual onset allow families some time for adjustment to the illness and time for family adaptation. Significant alteration of roles within the family may be necessary to compensate for the ill member. Illnesses which strike quickly place the entire family into an immediate crisis, with major readjustments compressed into a very short time frame.

Course

The course of chronic illness is essentially progressive, constant, or episodic. A progressive disease, such as Alzheimer’s disease, is one that is continuously symptomatic and progressive. Family members are faced with a symptomatic family member, whose condition is steadily worsening. They are challenged constantly to adapt roles and reorganize family structures to care for the ill member.

A constant-course illness is one in which the course stabilizes after an initial crisis event, such as a stroke. After the initial period of crisis and adjustment, families can stabilize the care for the chronically ill member.

The episodic or relapsing course is one which alternates stable periods of varying length with times of acute exacerbations or flare-up. Illnesses such as asthma or ulcerative colitis are examples of episodic diseases which require families to change roles back and forth, depending on the current health status of the ill member. The uncertainty and frequent role changes add tremendous stress to the family unit.

Outcome expected

The extent to which a chronic illness may cause death and the degree to which it may shorten one’s life span are crucial features distinguishing illnesses.

At one end of the spectrum are metastatic cancer or severe cardiomyopathy which pose an immediate threat to life. These types of diseases create an undercurrent of anticipatory grief and separation, and a sense of impending doom which affect all phases of family adaptation.

At the opposite end of the continuum are chronic conditions which normally do not threaten one’s life or typically shorten lifespan, such as blindness or migraine headaches. However, family adaptation in the non-life threatening illnesses must focus on long-term adjustments and stable, permanent realignment of roles.

Incapacitation

Incapacitation refers to an impairment of functioning due to a defect or severe disability. Incapacitation can result from impaired cognition, movement, or energy level, or from physical deformities or other medical causes of stigmas.

The type and severity of incapacitation is a very significant factor in determining the stress experienced by
families For example, the combined physical and cognitive effects of a stroke can stress the family more than an injury or illness which affects only the person's energy production while allowing retention of cognitive faculties

Assessing the four attributes of a chronic illness (onset, course, outcome, and incapacitation) is essential for nurses, in order to classify the chronic illness correctly, to identify the family stressors involved, and to develop nursing interventions for family care

The illness time line

Rolland (1989) described the natural history of chronic illness within three time phases: the crisis, chronic, and terminal phases. The crisis phase is initiated with first symptom onset and extends through diagnosis. This phase creates high stress for families who are shocked and angered by the sudden illness, and who are unprepared for the role changes and family adjustments required.

The chronic phase is the timespan from initial diagnosis through treatment and readjustment. The chronic phase requires prolonged adjustments and the establishment of a level of family normality to deal with the illness. The attempt by the family to maintain a semblance of normal life under the abnormal conditions of chronic illness is a key task for the entire family.

The final, terminal phase occurs when death becomes apparent and family grieving begins. This phase is marked by separation, death, grief, and resolution of mourning.

The three time phases illuminate critical transition points in the natural developmental phases of an illness. The interaction of the time phases and the typology of illness, provides a basis for nursing assessment and a framework to relate chronic disease with psychosocial and developmental tasks.

FAMILY SYSTEMS THEORY

The systems approach to the study of the family is based upon the theory derived from physics and biology by Bertalanffy (1968). A system is composed of a set of interactive elements, and yet each system is distinct from the environment in which it exists. An open system exchanges energy and matter with the environment to evolve toward greater order and complexity. This concept of negentropy can be adapted and applied to the family.

Rogers (1983) viewed the family as an 'irreducible, four-dimensional negentropic energy field. The family is viewed as an irreducible whole that is not understood by knowledge of individual members.' From this theoretical framework, the family is considered to be in a state of change which is continuous and innovative. Family characteristics are manifestations of the constant interaction of family with the environment. A theoretical approach relevant to health care must permit the study of the dynamic individual, the dynamic family unit, and their inter-relatedness (Whall & Fawcett 1991)

Clements & Roberts (1983) defined a family as a social system comprised of two or more persons who co-exist within the context of some expectations of reciprocal affection, mutual responsibility, and temporal duration. Gillis et al. (1989) offered a broader view of family that includes a three-generational group of individuals having close emotional bonds, who meet affectional, socio-economic, and socialization needs of one another and of the family system.

Wright & Leahy (1987) defined family health as a dynamic, relative state of well-being. Five dimensions, the biological, psychological, sociological, spiritual, and cultural, all combine into a holistic system. One measure of family health is the ability of the family to organize and rally in the face of challenge. When the family's resources are insufficient to meet the challenge, family stress occurs, and the family needs to seek outside help.

The family adaptation model, developed by Riehl & Roy (1980) views the family as an adaptive system with inputs, internal control and feedback processes, and output. In this adaptation model, the focus of nursing is a concern for the family as a unit on the health-illness continuum, with assessments and interventions directed toward helping patient and family to adapt. Families of chronically ill people incur many biological, psychological, and sociological losses, and there are no clear-cut norms of behavior for anyone involved (Craig & Edwards 1983). Adaptation is the ultimate family nursing goal in dealing with chronic illness (Pollock 1985).

FAMILY LIFE-CYCLE PERSPECTIVE

The development of a life-cycle perspective originated with the work of Erikson (1950) and was further defined by Duvall (1977). Duvall conceptualized the family life-cycle according to different transitional stages related to the coming and going of members, marriage, birth and raising of children, launching of children, retirement, and death.

When a family member is diagnosed as having a chronic illness, it may be helpful to simultaneously study the interaction of the individual and family. A central concept is that of the life-cycle. A cycle suggests an underlying order of the life course whereby individual, family, or illness uniqueness occurs within an unfolding time sequence.

Illness, individual, and family development have in common the notion of eras marked by constant changes in building and maintaining functions through transitional periods of development. Transition periods are potentially the most vulnerable because previous individual, family, and illness life structures are reappraised in light of new developmental tasks.
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Cicirelli (1985) stated that the family is considered as the motion of a three- or four-generational system as it moves through time. Families incorporate new members only by birth, adoption, or marriage, and members can leave only by death. Each family member has roles and functions, but the main value in families is in the supportive and nurturing relationships (Woods et al. 1989).

As shown in Figure 2, the individual who requires care is the centre of the family system. The family, which includes nuclear and extended members, surrounds the individual and provides both support and structure. The individual life-cycle takes place within the family life-cycle, and it is this interconnectedness that is the primary context of human development. The family life-cycle is enclosed within and closely connected to its community. The stability and health of the community may affect the functioning of the family system significantly. Similarly, the society in which the community exists may affect the social, cultural, political, economic, and religious status of each individual and each family unit. The health and normal functioning of each system level is, to some degree, dependent on the health of the other levels.

Family stresses, which are likely to occur around the life-cycle transition points, often result in disruption of the life-cycle and increased stress on the family (Walsh 1978). Carter (1978) outlined family stress and the flow of anxiety in a family as both vertical and horizontal stressors on a timeline. The vertical flow in a system includes patterns of relating and functioning transmitted down the generations of a family. It includes all of the family attitudes, expectations, and labels, and the taboos the children learn. Systems-oriented researchers have emphasized that a family's present response cannot be adequately comprehended apart from its history (Bowen 1978).

The horizontal flow in the system includes anxiety produced by stresses on the family moving through time. These include the developmental and transitional issues which normally occur in time. However, this also may include unpredictable, out of the ordinary life events, such as chronic illness.

Carter & McGoldrick (1989 p 8) suggested that the degree of anxiety engendered by the stress on the vertical and the horizontal axes at the points where they converge is the key determinant of how well the family will manage its transitions through life. Although all normative change is to some degree stressful, it has been observed that when the horizontal (developmental) stress intersects with a vertical (transgenerational) stress, there is a quantum leap in anxiety within the family system.

INTERFACE OF ILLNESS, THE INDIVIDUAL AND THE FAMILY SYSTEM AND LIFE-CYCLE

The concept of centripetal versus centrifugal family phases in the family life-cycle is particularly useful in examining the integration of family, individual, and illness development (Beavers 1982). This concept portrays a three-generational family system oscillating through time between periods of family closeness (centripetal) and periods of family distancing (centrifugal phases). Literally, 'centripetal' and 'centrifugal' describe a tendency to move towards and away from the centre. In life-cycle terms, they connote a fit between developmental tasks and the relative...
need for internally directed, individual and family energy to accomplish those tasks.

Chronic disease exerts a centripetal pull on the family system. The occurrence of chronic illness in a family sets in motion for that family a centripetal process of socialization to the illness (Beavers & Voeller 1983). The symptoms, role changes, and uncertainty associated with the illness all serve to refocus the family inwardly. If the onset of chronic illness coincides with a centrifugal period for the family, it can alter a family's natural momentum. Disease onset that coincides with a centrifugal period in the family life-cycle may result in a prolongation of the period. The inward pull of the illness may also coincide with a developmental phase of life-cycle with resulting increases in family stress.

When chronic illness is analysed through the lens of the typology and time phases of illness, it is apparent that the amounts of centripetal and centrifugal pull vary greatly. This variability has important effects on the family life-cycle, independent of the family dynamics.

The tendency for a chronic illness to interact centripetally with a family increases as the risk of incapacitation or death increases. Progressive diseases over long time phases are inherently more centripetal in their effect on family stress than are constant-course illnesses. Chronic illnesses occurring at unusual phases of the life-cycle tend to be more developmentally disruptive (Herz 1980). Levinson (1978) found that the timing in the life-cycle of an unexpected event, such as a chronic illness, will shape the family's adaptation and the event's influence on family development.

In the face of chronic illnesses, the goal for the family is to deal with the developmental demands of the illness while dealing simultaneously with their individual and family system development through the life-cycle.

CONCLUSIONS

This paper has presented a conceptual framework for analysing the interaction of chronic illness with family and individual life-cycles. The typology and time phase analyses provide a framework to generate and test hypotheses about the relationships of different components of family functioning and different phases of illness (Wright & Leahy 1987).

Knowledge concerning life-cycle stressors is essential for nurses, in order to delineate the relationships of the vertical and horizontal stressors and the centripetal and centrifugal forces which affect both the individual and the family system.

Used in conjunction with a comprehensive family systems theory, the life-cycle perspective can provide a theoretical framework for both nursing research and practice.

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