



CHRONIC ILLNESS AND AGING

SECTION 3: TYPOLOGY OF CHRONIC ILLNESS AND IMPACT ON THE FAMILY

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Synopsis

Chronic illness is a term applied to a broad range of diseases that vary greatly both in their essential characteristics and the ways in which they affect the family system and its adaptive functioning. To understand the most critical ways a chronic disease affects not only the family system as a whole but also the individual family members, one must consider the key characteristics of both the disease and the family system (Rolland, 1994). Rolland developed a typology of chronic diseases that categorizes diseases by a core set of four characteristics—onset, course, outcome, and degree of incapacitation—that are particularly relevant to the adaptive functioning of family systems. The impacts of chronic disease on the family system should be assessed in two essential domains: the family's instrumental functions as a social unit and the critical components of family functioning. The first domain, the impact of chronic disease, considers how the disease affects the family's capacity to fulfill its essential purposes: for example, providing material security for its members, providing for their developmental needs, and providing care and support for ill and disabled members. The second domain, the impact of critical components of family functioning, includes family structural and organizational patterns, communication processes, multigenerational patterns and the family life cycle, and family belief systems (Rolland, 1994).

A Typology of Chronic Disease

- ◆ Chronic diseases can be categorized according to four key dimensions that have an impact on the family system: onset, course, outcome, and degree of incapacitation (Rolland, 1994).

Disease onset: Onset of disease refers to the time dimension of how different forms of chronic disease are manifested. In particular, families must adapt differently when the onset of a disease is rapid and acute (as in a stroke) as opposed to when it is gradual (as in Alzheimer's disease).

Disease course: Chronic diseases differ greatly in the extent to which they are progressive, i.e., become worse over time (as in Alzheimer's disease), or are constant, i.e., remain relatively static or stable (as in osteoarthritis). In addition, some forms of progressive chronic disease entail periods of relative stability interrupted by dramatic setbacks or relapses (as in many cancers), whereas others manifest a highly consistent and relatively predictable course that is either gradual or rapidly downward (as in Type 2 diabetes or cardiac disease).

Disease outcome: Chronic diseases can be crudely characterized as fatal, contributing to a shortened lifespan, or nonfatal in their predictable ultimate outcome. Although many chronic diseases (such as diabetes) may shorten the life span and even be fatal in the long run, such nonfatal diseases offer neither a predictable timeline of demise nor a strong likelihood they will emerge as the principal cause of death (e.g., osteoarthritis). Fatal diseases (as in pancreatic cancer), on the other hand, entail a more direct confrontation with the high likelihood of death, calling for particular adaptive demands by the affected individual and the family system that are a part of the death and dying process.

Degree of incapacitation: Some chronic diseases have few direct or sustained effects on an individual's functional independence throughout most of their course, whereas other forms of chronic disease entail a significant degree of incapacitation and major adaptive responses by the family system.

- ◆ Chronic diseases can be categorized into distinct psychosocial typologies, each with its own set of implications for the adaptation and social functioning of the family system.

For example, an older adult with various forms of fatal cancer may be functionally independent until the final stages of disease despite the dismal prognosis. In contrast, some nonfatal diseases (e.g., Parkinson's disease), though they may shorten the lifespan, bring with them significant incapacities and ongoing adaptive demands on the family system. As a general point, the distinct psychosocial typology of a given disease is largely a function of the interactions between the four key dimensions of disease identified by Rolland (1994): onset, course, outcome, and degree of incapacitation.

Chronic Illness and the Family System: Domains of Impact

- ◆ Chronic disease affects the family system's instrumental functions as a social unit.

Throughout human history and across all human societies, the family system has organized itself to meet the demands of a set of critical instrumental functions, functions that are essential to both individual family members and society at large.

- First, primary among those functions is the family's role as an economic unit that provides for the essential material needs of its members: food, shelter, and clothing.
- Second, families function to meet the developmental and emotional needs of individual family members at whatever stages of the life course they happen to be in. Although young children, adolescents, young adults, middle-aged adults, and the elderly have different social and emotional demands on the family system, at no stage of the life course does human development unfold wholly and independently outside the family system.
- Finally, the family system functions as the primary care and support system for ill and disabled family members. Despite the existence of an extensive institutional long-term system of care consisting of nursing homes, rehabilitative facilities, and chronic care hospitals that serve as a substitute for the family system, the vast majority of disabled individuals (both young and old) are cared for by their families (Spector, Fleishman, Pezzin, & Spillman, 2000).

Family Tasks and Responsibilities in Providing Care to Older Persons

A recent report from the Institute of Medicine (2008) reviews the many roles of family members or informal caregivers in the management of health care of older persons.

- ◆ Informal caregivers assume many different responsibilities in providing care support for older adults (IOM, 2008).
 - They take responsibility for much of the patient's role with respect to logistics, care management, and medical decision-making. For example, they often schedule medical appointments for older adults, provide transportation, and handle billing questions.
 - They assume major responsibility in presenting the patient's history and listening to the clinicians' assessments and instructions. They frequently

make, or influence, decisions regarding the appropriate course of treatment. They also monitor the older person's health status.

- Caregivers take on the role of health care provider, providing assistance with the activities of daily living.
- Family members also advocate on the patient's behalf and to enhance the providers' understanding of the older adult's social environment, health conditions, and care preferences.
- Similarly, family members' understanding of the providers' treatment recommendations and their ongoing interactions with the patient at home and in the community can influence the patient's behaviors, treatment adherence, and health.
- Family members often serve as interpreters to health care providers when older adults do not speak English. An estimated 79% of hospitals rely frequently on family and friends to serve as interpreters (Wilson-Stronks & Galvez, 2007). However, due to the potential risk for inaccurate transmission of information several states have developed laws that restrict this practice.

Impact of Chronic Illness on the Family

- ◆ A chronic disease can adversely affect the family's instrumental functions in a variety of ways.

How a disease affects a family system depends on the nature of the disease itself (per the typology of chronic diseases described previously), the convergence of roles the person with the disease fulfills in the family (breadwinner, lover, primary parent to the youngest children, caregiver of an aged parent or spouse), and how the characteristics of the disease interact with the capacity of the affected family members to fulfill their normative family roles. Also, family members who are not the one with the chronic disease may have to adapt their roles in the family significantly to accommodate the caregiving demands imposed by the ill person. For example, the adult daughter of an elderly parent with advancing cancer may feel compelled by the conventions of gender socialization to act as her parent's primary caregiver despite the detrimental consequences to her career, the family income, and her emotional availability to other family members.

- ◆ The impact of chronic disease on critical components of family functioning can be dramatic.

Rolland (1994) identified four components of family functioning that can be affected dramatically by the nature and course of a chronic disease: 1) family structural and organizational patterns, 2) communication processes, 3) multigenerational patterns, and 4) the family life cycle, and family belief systems. The array of chronic disease morphologies, when combined with variations in how families both structure themselves and adapt to disease, pose formidable challenges to the family assessment process. However, delineating the process of assessment by these four components of family functioning enables the clinician to at least gain a firm grasp on how a given disease process has affected a family.

- 1) The structural and organizational patterns of a family system refer to both the structural constellation of the family and the functional dimensions of adaptability, cohesion, and pattern of relationships within the family (Rolland, 1994).
- 2) The family communication component includes the degree of open and direct communication versus latent and constrained communication, patterns of family member inclusiveness, ways of handling risky or painful topics, and family secrets.
- 3) Family multigenerational assessment entails how families have adapted to various kinds of adversity and evolved over time. That is, every disease or crisis that confronts a family is contextualized in a family's historical experience and acquired patterns of adaptation and ultimately is incorporated into the family's further evolution.
- 4) Finally, families have "belief systems" (shared constructions of reality, world views) that both reinforce family identity and enable families to make sense of everyday complexities and crises, including crises that are introduced by the onset and progression of chronic disease.

For example, many families hold to the belief (found in many religious traditions) that the episodes of crisis that accompany the progression of illness represent a "test" of the family's faith and fortitude. While this belief may enable some families members to "make sense" of the crisis at hand and the losses that may accompany it (e.g., as in the loss of an aging parent's capacity to speak due to a stroke), for other families it may seem that a new crisis represents a divine reaction to a failure of faith (e.g., "we failed to place mother's recovery in God's hands..."). Another belief that is commonly held among families is the belief that "we always stick together and take care of our own." As noble and as historically true as this might have been, sometimes a new crisis in the progression of a chronic disease provokes divisions among family members (e.g. disagreement among siblings over who should manage a cognitively impaired parent's

finances) and may signal a level of incapacity that the family in fact does not have the resources to respond to (e.g. as in “We always said to Mom we would never allow her to go to a nursing home, how can we break our word to her?”). A social worker’s ability to help a family navigate the crises that accompany the onset and progression of chronic illness often requires some sensitive interrogation into the core family beliefs that families use to define themselves, make sense of losses, and draw upon for sources of resilience and unity.

Application of Rolland’s Model to Understanding Family Influence on Type 2 Diabetes

- ◆ Type 2 diabetes provides a particularly useful exemplar of chronic disease and the family

Chesla et al. (2003) applied key aspects of Rolland’s model (family structure and organization, world view, and management of emotions) to a prospective study of family influence on Type 2 diabetes in a multiethnic sample of 113 European American and 74 Latino American patients and their families. Type 2 diabetes provides a particularly useful exemplar of chronic disease and the family because 1) it is increasing in prevalence in the general population, 2) a high proportion of older adults develop Type II diabetes as a part of the aging process, 3) management of Type II diabetes entails often significant adaptation by the patient and as well as the family system, and 4) research suggest that the family context provides important influences over the course and speed of progression of the disease, just as it does in a range of other chronic diseases.

Three domains of family context and their impact on diabetes management were assessed over the course of one year. Disease management includes diabetes self-care, quality of life, emotional well-being, and biological markers of disease status and overall health.

Although several findings with relevance to practice with families were identified, three appear particularly relevant. First, higher levels of unresolved conflict for European American and Latino families were predictive of negative changes in some aspects of disease management. In the case of European American families, conflicts over diabetes disease management contributed poorly regulated eating. Among Latino families, conflicts predicted worse scores on disease specific quality of life measures (Chesla et al., 2003). Second, family organization and structure did not seem especially predictive of disease management for either group. Third, the indicator for family world view appeared to act in radically different ways for Latino families relative to their European American counterparts. For European American families, a more coherent world view predicted positive changes in diabetes disease management,

whereas for Latino families higher levels of coherence predicted negative changes in disease management (Chesla et al, 2003). The authors of this study speculated that among Latino American families (as opposed to their European American counterparts), a negatively coherent world view may be more highly correlated with the kind of realism that is needed to manage disease effectively in the face of their relative structural disadvantages.

These findings suggest that social workers should devote primary attention to the context of family conflict, rather than to structural and organizational patterns and, further, that the role of family belief systems in the management of chronic disease may differ significantly across cultures. Both specific attention to the sources of family conflict and pathways to their amelioration, and the ability to understand how family belief systems interact with diseases processes can serve as powerful points of leverage as social workers seek to enhance the disease management capacities of families.

Impact of Family on Health Outcomes of Older Adults

- ◆ The IOM (2008) report documents strong evidence that informal caregivers have a profound effect on long-term care processes and outcomes.
 - Dementia care outcomes for patients are improved when families are engaged in patient care (Mittelman, Haley, Clay, & Roth, 2006).
 - Families enable postponement of institutionalization of the older person (Miller & Weissert, 2000), and are associated with shorter stays in the hospital (Picone, Wilson, & Chou, 2003).
 - The converse is also true, that is, that an absence of adequate caregiving is associated with problematic hospital discharges (Procter, Wilcockson, Pearson, & Allgar, 2001) or readmissions (Lotus Shyu, Chen, & Lee, 2004).
 - Individuals with few social supports are more likely to have unmet needs in personal care and household tasks (Lima & Allen, 2001) and are also more likely to miss medical appointments and to fail to fill prescriptions (Allen & Mor, 1997).
 - A meta-analysis of 122 studies found that patients who received instrumental assistance were 3.6 times more likely to adhere to medical instructions and prescriptions (DiMatteo, 2004). This was twice as effective as emotional support, which was associated with 1.8 times greater likelihood of adherence. The effect of family support varies, however; individuals with close and cohesive families are 3 times more likely to adhere to instructions than those from conflicted families.

Although the importance of family involvement in the process of health care delivery is recognized, there is still little knowledge about which particular attributes of family involvement are efficacious in improving health outcomes (IOM, 2008).

References

- Allen, S. M., & Mor. V. (1997). The prevalence and consequences of unmet need. Contrasts between older and younger adults with disability. *Medical Care*, 35(11), 1132-1148.
- Chesla, C. A., Fisher, L., Skaff, M. M., Mullan, J. T., Gilliss, C. L., & Kanter, R. (2003). Family predictors of disease management over one year in Latino and European American patients with type 2 diabetes. *Family Process*, 42, 375-390.
- DiMatteo, M. R. (2004). Social support and patient adherence to medical treatment: A meta-analysis. *Health Psychology*, 23(2), 207-218.
- Institute of Medicine. (2008). *Retooling for an aging America*. Washington, DC: The National Academies Press. Available at <http://www.nap.edu/catalog/12089.html>
- Lima, J. C., & Allen, S. M. (2001). Targeting risk for unmet need: Not enough help versus no help at all. *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences* 56B(5), S302- S310.
- Lotus Shyu, Y., Chen, M., & Lee, H. (2004). Caregiver's needs as predictors of hospital readmission for the elderly in Taiwan. *Social Science & Medicine*, 58(7), 1395-1403.
- Miller, E. A., & Weissert, W. G. (2000). Predicting elderly people's risk for nursing home placement, hospitalization, functional impairment, and mortality: A synthesis. *Medical Care Research and Review*, 57(3), 259-297.
- Mittelman, M. S., Haley, W. E. Clay, O. J., & Roth, D. L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer Disease. *Neurology*, 67(9), 1592-1599.
- Picone, G., Wilson, R. M., & Chou, S. (2003). Analysis of hospital length of stay and discharge destination using hazard functions with unmeasured heterogeneity. *Health Economics*, 12(12), 1021-1034.
- Procter, S., Wilcockson, J., Pearson, P., & Allgar, V. (2001). Going home from the hospital: The carer/patient dyad. *Journal of Advanced Nursing*, 35(2), 206-217.
- Rolland, J. (1994). *Families, illness, and disability: An integrative treatment model*. New York: Basic Books.
- Spector, W. D., Fleishman, J. A., Pezzin, L. E., & Spillman, B. C. (2000). *The characteristics of long-term care users*. Rockville, MD: Agency for Health Care Policy and Research.

Wilson-Stronks, A., & E. Galvez. (2007). Hospitals, language, and culture: A snapshot of the nation. Retrieved August 11, 2008, from http://www.jointcommission.org/NR/rdonlyres/E64E5E89-5734-4D1D-BB4D-C4ACD4BF8BD3/0/hlc_paper.pdf

Curriculum Resources



Suggested Readings:

- Rolland, J. (1994). *Families, illness, and disability: An integrative treatment model*. New York: Basic Books.

This book, though somewhat dated by contemporary standards, remains available in either new or used editions. Although it is not specifically focused on the aged, both Rolland's multigenerational framework and the dynamics of chronic disease he illuminates are highly relevant to social work practice with the aged and their families. Rolland applies an ecosystem perspective to the family assessment process that is skillfully integrated with a readily interpretable typology of chronic disease. His book provides remarkably coherent syntheses of the literatures on the family and on the nature of chronic illness from medical anthropology, medical sociology, behavioral medicine, psychology, and social work, and then weaves it all into an incredibly pragmatic framework for clinical practice.

As alternatives to acquiring Rolland's book, the following two articles by Rolland precede the book and explicate Rolland's conceptual framework of chronic disease and family processes:

- Rolland, J. (1984). Toward a psychosocial typology of chronic and life threatening illness. *Family Systems Medicine*, 2, 245-263.
- Rolland, J. (1987). Chronic illness and the family life-cycle: A conceptual framework. *Family Process*, 26, 203-221.
- Fisher, L., & Weihs, K. (2000). Can addressing family relationships improve outcomes in chronic disease. *Journal of Family Practice*, 49, 561-566.

This article is a highly informative review written by researchers affiliated with the National Working Group on Family-Based Interventions on Chronic Disease. The authors identify important mechanisms through which the family's relational context affects disease management, then describe how particular characteristics of family relationships can function as risk or protective factors for disease management. In addition, major forms of family-based interventions are provided, linked to a review of the findings from selected clinical trials, which in turn are extended to applications for clinical practice. The authors first note two principal mechanisms through which the family context influences the course of chronic disease. The first mechanism is broadly described as the emotional climate, in essence the quality of attachments in the family and the degree of hostility and conflict present and their effect on the physiological

disease and stress-response processes in the identified patient. The second mechanism is the family's capacity to organize itself around the adaptive demands of the disease: e.g., accommodating numerous clinic appointments, dietary restriction, losses in functional capacity, and the difficult role changes for family members that might result. The review of the literature is divided into two segments. The first segment pertains to the identification of family characteristics that function as risk and protective factors in the management of chronic disease. The second segment examines the findings from selected clinical trials of family centered interventions in the context of chronic disease management, specifically psychoeducational approaches, relationship-focused interventions, and more intensive couples or family psychotherapy. Although most of the intervention studies reviewed involved the families of nonelderly patients, many of the findings appear to be relevant to diagnosis and intervention with families at all stages of the life course. Moreover, consistent with Rolland's framework (1984, 1987, 1994), it appears that the typology of disease is as relevant as the stage of aging or the family life cycle under consideration.

- Glasgow, R., Strycker, L., Toobert, D., & Eakin, E. (2000). A social-ecologic approach to assessing support for disease self-management: The chronic illness resources survey. *Journal of Behavioral Medicine, 23*, 559-583.

In research supported by the Robert Wood Johnson Foundation, Glasgow et al. described the structure, application, and psychometric properties of a social support survey based on a multilevel social-ecological model that was tested on a sample of adults with an array of chronic diseases (mean age, 63; range, 40 to 88 years). Because it interrogates eight distinct levels of psychosocial environmental support (physician and health care team, family and friends, personal actions, neighborhood, community, media and policy, community organizations, and workplace), the survey instrument offers a highly comprehensive approach to the person-environment psychosocial assessment essential to the management of chronic disease. The Chronic Illness Resources Survey (CIRS) has two versions: a 64-item full instrument and 29-item Brief CIRS. The authors described a prospective evaluation with the 123 patients having heart disease, arthritis, diabetes, and/or chronic obstructive pulmonary disease and revealed that the overall instrument and its subscales all met at least acceptable standards for internal consistency, test-retest reliability, and construct validity. Even more impressive, the authors assessed the predictive validity of the subscales in a 4-month prospective evaluation of chronic disease management and uncovered promising results suggesting various ways the scales might be directly applied to patients and families struggling with the management of chronic disease. The CIRS can be reasonably useful as a baseline diagnostic tool to determine whether, and in what areas, family level intervention is indicated, then be used later at different time points to assess whether intervention efforts are being effective in promoting positive change. Both the full and brief versions of the CIRS are provided in an appendix.



Case Study: Chronic Illness and the Family:

Inez B. is a 68-year-old woman who was initially referred to a community clinic after a fainting episode that occurred during her part-time shift at Wal-Mart. Aside from modest obesity and hypertension, the clinic's health care team discovered that Inez has Type 2 diabetes, advanced to the point where careful management of her disease, including insulin therapy, is required. In fact, Inez is already showing symptoms of peripheral vascular disease secondary to uncontrolled diabetes. Her primary care physician referred her to the clinic social worker because of significant concerns about her social situation and her ability to manage her disease effectively.

The following information was available from the limited social history in her clinic records: Inez is a naturalized citizen who emigrated from Mexico 23 years earlier along with her husband and three young children. Her command of English is limited, she is functionally illiterate, and she currently relies on her adult children to help her with complex written information. Aside from the limited income Inez brings home from her part-time job, she and her husband have only his Social Security Old Age Insurance benefits. Inez does all the housework and the cooking for her husband and herself and provides meals and day care for three of her grandchildren while their parents are at work.

The following exercise consists of three elements:

- 1) Using the Typology of Chronic Disease framework shown in Table 1, identify the characteristics of Inez's diabetes and her hypertensive disease.

[Note to instructor: Students should note that both hypertensive disease and insulin-dependent adult onset diabetes are shown on Table 1 to fall in the cell designated for diseases that are gradual, progressive, and associated with a shortened life span. The speed of disease progression in both adult onset diabetes and hypertension, as well as their respective effects on a shortened life span, are largely determined by how well the diabetic patient can manage their disease, which in turn is heavily influenced by access to appropriate health care and the support they receive from their family. Several of your students are likely to have someone in their family managing insulin dependent-diabetes, and it often works well to have these students describe what is entailed for the person; this then can be applied to the situation of Inez and her specific challenges.]

- 2) Investigate the kinds of adaptive demands that diabetes and hypertension place on Inez and her family system. Be as specific as possible regarding each disease.

[Note to instructor: Several of your students will likely have someone in their family managing insulin-dependent diabetes, and it often works well to have these students describe to the class what is entailed for the person managing this disease (e.g., planning every meal and snack, recognizing and balancing the effects of stress and

exertion on blood sugar levels and insulin dosing, rigorous and sometimes painful monitoring of blood sugar). This then can be applied to the situation of Inez and her specific challenges as described in her brief social summary. For example, diabetes educational materials are often written with at least a high school level of literacy assumed; thus, even should they be made available in Spanish, Inez will not necessarily be able to comprehend them. Further, Inez has a very limited income with which to pay for her anti-hypertensive medications, glucose sticks, and insulin. Finally, the early onset of peripheral vascular disease signals the possibility that she will not be able to sustain demanding work that keeps her on her feet for long hours. Health insurance coverage and access to health care are also large issues. In addition, students should think about the role that Inez has fulfilled in the family as the prime caregiver for her husband and children, and the kinds of adaptive demands implied for the family should Inez be supported by her family in managing her disease effectively.]

- 3) What kinds of questions or areas of exploration should the social worker pursue in the biopsychosocial assessment process?

[Note to instructor: Students should be encouraged to identify the information they have in hand, both about Inez and the nature of her disease processes. This then helps them to identify critical elements of information that they do not know—some of which might be acquired via patient/family interviews and some of which can be gathered from other sources (e.g., disease and disease management information via library resources and the internet). The most critical elements of information pertain to Inez's experiences with and beliefs about diabetes—in particular her beliefs about disease prognosis and the capacity of the patient to influence the course of the disease. Another line of inquiry pertains to the sources of motivation and capacity that will support Inez's adaptation to the specific demands entailed in a rigorous regime of disease management. A third line of inquiry pertains to material resources and health care system access. Also, students should be advised that a complete biopsychosocial assessment, ideally, would entail more than one interview, because the patient needs time to absorb information about the disease and the implications for her life to be a more effective informant. Some students might suggest this is unrealistic—which then could be used as a basis for a discussion on tensions between the organization of the health care system and the nature of successful behavioral interventions].

NOTE: The Stanford Geriatric Education Center is a good resource for students to explore the impact of diabetes on mental health among diverse populations. Available at:

http://sgec.stanford.edu/diabetes_mh.html