
Women with Chronic Illness: Overcoming Disconnection

Maureen Reid-Cunningham, LICSW, Dana Snyder-Grant, LICSW, Kitty Stein, Psy.D., Elizabeth Tyson, M.A., CCMHC, & Barbara Halen, M.A.

About the Authors

All the authors are members of the Stone Center Study Group on Women with Chronic Illness and Disability. Maureen Reid-Cunningham, MSW, is a social worker in private practice in Cambridge, Massachusetts; she writes and consults on chronic illness issues. Dana Snyder-Grant, MSW, is a social worker who runs psychotherapy groups for individuals with chronic illness at Eliot Community Human Services in Concord, Massachusetts and the National Multiple Sclerosis Society in Waltham, Massachusetts; she writes and speaks on chronic illness issues. Kitty Stein, Psy.D., is a psychologist in private practice in Brookline and Lincoln; she is also on the faculty of the Couples and Family Therapy Training Program at Cambridge Hospital. Elizabeth Tyson, M.A., LMHC, is a psychotherapist in private practice in Chelmsford and Shirley, Massachusetts. Her specialty is breast cancer treatment and issues of living with life-threatening illness. Barbara Halen, M.A., is an educator and trainer; she has relocated to Costa Rica for health reasons.

Abstract

Within the framework of Relational/Cultural (R/C) Theory, five psychotherapists and educators offer new ideas about how women can live well with adult-onset chronic illness. After reviewing R/C Theory, the authors identify the processes of recognition, renegotiation, and regeneration, which they refer to as "The Three Rs." These processes provide a useful framework for understanding the development of women who must cope with chronic illness. The authors illustrate their points by sharing their personal stories.

Diversity is a major theme in the '90s. We believe that the spectrum of diversity should be broad enough to include people with chronic illness or disability. In 1994, with the encouragement and support of Jean Baker Miller and the Stone Center, a call was issued for group members who were interested in exploring how women's psychological growth continued through the experience of developing and learning to live with a chronic illness or disability.

Over time, a core group of five members has evolved: four of us are therapists and one is a cross-cultural trainer/educator. Each of us is living with a chronic illness. There is no widely accepted term for the particular segment of the population that we represent. For purposes of clarity, in this paper we define the group of people with adult onset chronic illness (AOCI) as those who have a non-congenital condition. The onset of illness occurs in adulthood when the individual has already established a sense of identity. We include those with cancer and AIDS within our umbrella definition because of the commonalties we have found. The term chronic illness, for the purpose of brevity, is intended to include adult onset disabilities as well.

We are white, educated, heterosexual, and middle class, with a wide range of economic circumstances. While we do not directly address economic issues, we are all aware that access to sufficient, reliable income and quality health care are crucial aspects of coming to terms with a chronic illness. We have tried to be mindful of the uniqueness of our experiences and circumstances and do not intend to speak for women of different backgrounds.

We write about women's experience, as that is ours (and much that is written is only about men, and usually doesn't value relationships). While we do not argue that this experience excludes any parallels with men, we focus on women's psychological

development and how it interacts with illness and disability.

Increasingly we speak about the personal meaning of the dramatic life-changing events imposed by the development of a chronic illness, and we have searched for the common threads in our experience. We have discovered that, for each of us, living successfully with a chronic illness has been a process of recognition of the changes and their implications, renegotiation of identity through relationships, and regeneration as we continue to grow and develop with the experience of illness. We think that our stories demonstrate the processes of **recognition**, **renegotiation**, and **regeneration**.

A Relational Approach

Relational/Cultural Theory provides a framework for understanding the ways in which we respond to, and continue to develop with, the experience of chronic illness. For women, relationships—the inner sense of connection with others—are the central feature of development. Connection is key to development, not separation/individuation, as has been postulated by traditional psychodynamic theories. Mutual interaction, in which both people participate and enlarge themselves, others, and their connections, is essential for enhancing growth (Miller, 1984; Surrey, 1985; Jordan, 1991).

It has become clear to us that the quality of our relationships is central to our ability to live successfully with illness. That quality can, in fact, facilitate or hinder our ability to cope. The denial of illness from a loved one can challenge one's own recognition of and adaptation to illness, while support and reciprocity can foster one's process of coming to terms with illness. Such connections come from a variety of sources—spouse, parent, child, friend, professional, or members of formal and informal support groups.

In considering the connection between relationships and the vicissitudes of chronic illness, we state emphatically that relationships, no matter how positive or plentiful, are not curative. Suggesting otherwise places an unfair burden of guilt and/or shame upon people who have chronic illnesses.

It is critical to understand that relationships that provide the most emotional healing are not one-sided, intended only to provide care for the one who is ill. The relationships are mutual, with care flowing in both directions. Judith Jordan states that “the relational perspective stresses ‘being-in-relation,’ an

interactional, ongoing ‘process of being’ rather than a static structure dedicated to increasing self-sufficient functioning” (Jordan, 1997, p. 29). We have come to realize that, although our physical health has changed, our capacity to “be-in-relation,” to care for, be empathetic to and connect with others, remains. Mutual relationships are key to living with chronic illness.

The Three R's

The diagnosis of AOCI is a profoundly life-altering event. The change in a woman's health and the resulting physical and emotional shifts are extremely upsetting. The qualities of health she once took for granted in her body—these can include function, mobility, strength, appearance, energy level, and/or healing ability—are not as they were. Since many illnesses can be debilitating and painful, as well as life-threatening, this can be a frightening and disheartening time in a woman's life. The process of moving forward and coping can seem impossible, for so much has been changed and lost. Life no longer presents itself in a way that is predictable and easily understood. Rather, it is more often unpredictable in nature.

Living well with chronic illness can be achieved. We have identified the concepts of **recognition**, **renegotiation**, and **regeneration** as key to a woman's adaptation to living with chronic illness. These processes are nonlinear. They are cyclical, recurring throughout a woman's lifetime. The wide breadth of these experiences can range from practical to existential.

Recognition is the conscious awareness of a serious change in health status. It is a process that is separate from, but related to, a diagnosis, in that one can be acutely aware of a shift in health long before medical confirmation. Each woman needs to move into understanding that this illness may profoundly change the way life will be—including the possibility of a shortened life span. Recognition takes many forms; it is a lifelong process that involves mourning losses and identifying changes that can occur daily.

The process of recognition addresses the existence of illness as well as its effect on women's relationships. The traumatic impact of the chronicity of illness may lead to disconnection. A woman may isolate herself out of fear and shame, while significant others may withdraw in response to their own reactions. Ideally, connection will be maintained and others can assist a woman with ownership of her illness by their willingness to both hear her experience