Living with Chronic Illness: The Interface of Stigma and Normalization

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Traditionnellement, les chercheurs ont étudié et interprété l'expérience de la maladie chronique selon une analyse qui est soit axée sur le stigmate, soit axée sur la normalisation, mais très rarement en utilisant les deux facteurs simultanément. Lorsque la maladie chronique est examinée à l'aide d'une analyse axée sur le stigmate, les résultats ont tendance à mettre en lumière la manière dont l'individu souffre du stigmate. Lorsqu'elle est étudiée selon une analyse axée sur la normalisation, les résultats ont tendance à articuler les moyens utilisés par l'individu pour atteindre la normalité malgré sa condition chronique. Cet article fait état des implications liées à une démarche qui cible une ou l'autre de ces deux perspectives. Selon les auteurs, les chercheurs peuvent saisir et comprendre l'expérience dynamique et en évolution des personnes atteintes de maladies chroniques en étudiant l'interdépendance des deux perspectives et en évitant de tirer des conclusions inhérentes soit au stigmate, soit à la normalisation. L'intégration des aspects liés au stigmate et à la normalisation dans l'expérience de la maladie chronique, en interaction au fil du temps, favorisera une compréhension plus grande et plus raffinée du vécu complexe des gens aux prises avec des conditions chroniques.

Traditionally, researchers have studied and interpreted the chronic illness experience through a lens of either stigma or normalization, but rarely both simultaneously. When chronic illness is examined through a stigma lens, the findings tend to focus on the manner in which the individual suffers from the stigma. When it is examined through a normalization lens, the findings tend to articulate the ways in which the individual achieves normalcy despite having a chronic condition. This paper discusses the implications of assuming either of the two perspectives independent of the other. The authors argue that, in order to capture and understand the dynamic and evolving experience of people with chronic conditions, researchers should consider the interdependence of the two perspectives and avoid assumptions that derive from stigma or normalization alone. Considering stigma and normalization aspects of a chronic illness experience, in interaction over time, will facilitate a broader and more accurate understanding of the complex experience of people coping with chronic conditions.

Many diseases have shifted from acute life-and-death problems to chronic long-term trajectories. As a result, more and more members of society are experiencing a form of being different from what is consid-

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ered ideal or normal — that of having a chronic condition. The term *chronic condition* covers medically diagnosed diseases as well as chronic states such as disabilities. The chronic condition may be visible to others (such as paraplegia or a limb deficiency), be invisible to others (such as diabetes or inflammatory bowel disease), or have both visible and invisible manifestations (such as scleroderma or AIDS). In general, a chronic illness experience is a dynamic state of many facets including but not limited to physical or psychological problems caused by the condition and psychological stress imposed by society as a result of how it views the condition. As with any dynamic state, all of these aspects are subject to change over time and context.

Traditionally, researchers have studied and interpreted the chronic illness experience from one of two discrete conceptual vantage points: the stigma that society imposes on those who are judged to be different; or the success that people with chronic illness achieve, and the adjustments they make, as they normalize their experiences. These two conceptualizations have led to the development of research-based chronic illness theory that is presented through a lens of either stigma or normalization, but rarely through both lenses in the same person or population.

The purpose of this paper is to critically analyze what it is that researchers learn when they study the chronic illness experience from the singular perspective of the stigma lens or the normalization lens. From this analysis, an argument will be made that these approaches limit the researcher's ability to appreciate the inherent interdependence of the two phenomena as they shape a given chronic illness experience. We believe that examination of the two perspectives together will serve to enhance our understanding of the complexities of the chronic illness experience. By recognizing the unique vision that each lens provides, researchers will, we believe, be better able to appreciate the richness and scope of the experience than is possible under the constraints of a singular view.

Stigma

The study of chronic illness through a stigma lens has informed our understanding of many different conditions, but especially those that have particular social implications such as AIDS (Laryea & Gien, 1993), psychiatric disorders (Brunton, 1997), epilepsy (Iphofen, 1990), or rectal cancer (Macdonald, 1988). Inherent in these illnesses is the identification of the sufferer as in some way different. The word *stigma*, from the Greek, means something bad or unusual about a person (Goffman,

1963). Stigmatization is the process by which a society bestows its own negative meaning on the behaviours, signs, or attributes of an individual. Throughout history, for example, epilepsy and mental illness have been associated with evil and the devil (Fabrega, 1991; Lennox & Lennox, 1960). It is interesting to note that conditions that are stigmatized in one culture may be revered in another. Age-related changes, for example, are dreaded in Western society yet respected and even admired in other societies.

The original work on stigma, conducted by Goffman (1963), conceptualizes three types of stigma. The first is *physical deformity*. While many chronic illnesses, such as arthritis, can cause visible changes, Goffman explains that the more the deformity differs from the prevailing norms and desirability in the culture, the more stigmatizing it will be. The second is *character blemishes* such as dishonesty or a weakness that society may view as causing an illness. The person with liver cancer who is also an alcoholic may be greatly stigmatized, since he or she not only has a devastating illness but also might be seen as causing it by drinking excessively. The third is *tribal stigma*, by which those of a particular race or religion are seen as different from or in opposition to the norm.

Phillips (1990) conceives an outcome of disability as labelling, such as the identification of a person as "damaged goods" or "spoiled identity." According to Phillips, the stigma is caused not by the disability itself but by the difference between what is socially desirable and what in fact *is*. Susman (1994) describes stigma as a perceived negative difference between one individual and others because of a particular trait. Thorne (1993) theorizes that a person with a visible disability or chronic illness is actually rendered invisible by the reactions of others.

Jones et al. (1984) conceptualize a process of stigmatization by which people react to individuals who are different by discriminating against them. This process includes the construction of a belief system that enables people to apply labels such as "crippled" or "defective," rationalizing that those thus labelled pose a danger to them. Others maintain that the sight of a chronically ill person reminds healthy people of their vulnerability, making them fear that they might be afflicted with the illness themselves (Jones et al.; Katz, 1981).

In discussing the process of stigmatization, Goffman (1963) concludes that an individual is discredited if he or she shows any visible sign of difference. When the illness is not immediately visible, however, such as in the case of well-controlled seizures, the individual is discredit*able* but not yet discredit*ed*. The discreditable person must make a

decision — to disclose or not to disclose. The risks of disclosure are seen as being discredited and stigmatized, losing control of one's emotions, and being rejected (Charmaz, 1991). Schneider and Conrad (1983) conclude that the stigmatized learn about the extent and meaning of the stigma through contact with those who have rejected and ridiculed them. Scambler and Hopkins (1986) further observe that the stigmatized typically first learn to accept the process within their own families.

The research literature on the experience of chronic illness reveals that those who examine it through a stigmatization lens view social values and their enactment as the source of the stigma. The conclusion of such research usually is, therefore, that stigmatization is not within the control of the individual. This conceptualization portrays the person with a chronic condition as a victim of the prevailing norms.

Normalization

In contrast, many other chronic illness researchers have focused on the process of normalization. Researchers who study chronic conditions through a normalization lens describe the process as one of actively adapting to changes wrought by the condition. Schwartz (1957) and Davis (1961, 1963) were among the earliest chronic illness researchers to describe normalization as a positive response to an illness or disability. This tradition conceptualizes the process as one in which the person chooses to function effectively and be perceived as normal (Deatrick, Knafl, & Murphy-Moore, 1999). Many researchers view normalization as enabling individuals with a chronic condition to resume their pre-illness roles and responsibilities, such as finding ways to live, or to pretend to live, a normal life while coping with symptoms and minimizing the disability (Strauss et al., 1984). These researchers often cite the cases of people who have made extraordinary and heroic changes in order to thrive in the face of their chronic condition.

Some researchers have deemed normalization to be the most common management strategy among persons with a chronic condition (Darling & Darling, 1982). Goffman (1963) expresses the main goal of stigmatized people as being accepted by "so called normals." In Goffman's view, the more that individuals present themselves as normal, the less likely they are to be discredited and stigmatized. Thorne (1993) reports that to be normal means to "fit in." Implicit in the notion of fitting in is the view that being normal is the opposite of being discredited, with the fear and alienation that accompany the discredited

state. The process of normalization has been described as creating a positive attitude towards living with a chronic illness (Thorne).

Goffman (1963) conceptualizes "covering" as a strategy to hide the stigma-causing attribute and thereby deflect attention from it. Tactics include joking and attributing symptoms to something other than the disability or chronic illness. Thus a discreditable person may attempt to pass for normal by concealing the condition from others. Sometimes a person with a chronic condition will attempt to control the stigma by being highly selective about the individuals to whom he or she reveals the condition and relying on them to withhold the information from others. Charmaz (1991) notes that in some circumstances disclosure is associated with increasing support from select individuals or groups. A person with a chronic condition who successfully "passes" becomes part of the normal, healthy population. Passing for normal therefore causes immense stress, as the individual worries about being found out and caught in a lie (Goffman; Thorne, 1993). For example, a diabetic who passes for normal and then has a diabetic reaction might be embarrassed by the lie and subsequently stigmatized to an even greater degree.

In contrast to this view, some researchers see chronic illness sufferers and their families who engage in normalization as perceiving and describing their lives as normal even in the face of numerous difficulties. Miller (2000) theorizes that normalizing requires an ability to see life and all of its challenges as normal. In her typology of coping tasks of chronically ill adults, Miller includes maintaining a sense of normalcy. She describes normalizing as keeping the signs of the illness under control and out of sight. In order to achieve a state of normalcy, one must interpret one's abilities as similar to those of others. Focusing on children and families coping with a chronic condition, Knafl and Deatrick (1986) performed a concept analysis of normalization, later revising and refining their analysis to expand this view (Deatrick, Knafl, & Murphy-Moore, 1999). Their refined attributes of normalization include acknowledging the condition and its potential threat to lifestyle, adopting a "normalcy lens" for defining child and family, engaging in parenting and family behaviours that are consistent with the individual/family's view of normal, and interacting with others based on the perception of their situation as normal.

In the tradition of normalization, Antonovsky (1979) found that the ability to cope with a chronic illness was determined by the individual's sense of coherence. He refers to coherence as a global orientation that conveys the belief that stimuli are structured, predictable, and explain-

able and that there are resources to meet the demands of the stimuli as they are presented and as they change. Kadner (1989) describes resilience as a resource that promotes coping abilities. Social support has also been cited as a useful force for people with a chronic condition (Tilden & Weinert, 1987). Researchers linking social support to normalization have found that it helps people with chronic conditions develop a more positive sense of themselves (Charmaz, 1987; Cooper & Burnside, 1996, Halm; 1990, Woloshin, Schwartz, & Tosteson, 1997).

Royer (1998) describes normalization as a process of maintaining a positive self-image and retaining a sense of mastery while learning to function in a new role with new responsibilities. Royer reports that people who engage in normalization downplay their limitations in order to go on living as before. In order to do so, they may redefine their life's goals in light of what is now possible. They control negative emotions such as anxiety and depression in order to manage the illness. The final normalization task described by Royer is fighting alienation and stigmatization to prevent social isolation. The severity and visibility of the symptoms, along with the degree of unpredictability and the extent of personal resources, determine whether normalization is possible.

Royer (1998) also describes a process of "supernormalizing," whereby people use cognitive and behavioural strategies to achieve an extreme form of normalization. Royer describes supernormalization as a process of overcoming or denying that there are things one cannot do, of being distracted from discomfort, and of being encouraged to live as before.

Paterson, Thorne, Crawford, and Tarko (1999) cite personal transformation as important in achieving a state of health in the face of a chronic illness. They describe personal transformation as a process by which one responds to the challenge of coping with a problem and as an evolutionary change whereby some people find new ways of coping with a problem. O'Neill and Kenny (1998) cite spirituality as an important factor in maintaining a sense of well-being in chronic illness. Similarly, Kylma and Venvilainen- Julkunen (1997) refer to spirituality as crucial in maintaining a sense of hope.

In an early study of normalization in rheumatoid arthritis, Wiener (1975) identified six categories of normalization. *Covering up* involves the concealment of one's visible problems. *Keeping up* involves an attempt to maintain the pre-illness schedule, usually resulting in exhaustion. *Justifying inaction* refers to the process of explaining why one cannot participate in scheduled activities. *Pacing* refers to the bal-

ancing of activity and rest that enables people to participate in activities that make them appear normal. *Eliciting help* is the solicitation and utilization of help in order to keep up with activities. *Balancing the choices* is a decision-making process whereby chronically ill persons balance their activities in order to appear normal or, at times, give in and accept help, thus relinquishing their state of being normal.

In a study of people with congenital limb deficiencies, Frank (1988) found that instead of attempting to hide their condition, some people treated even a radical disability as normal for them. In this study, people used two major normalizing and coping techniques to deal with perceived stigmatization in their lives: acting as a political activist for those with disabilities and educating the public about them. Mechanic's (1995) work brings normalization into the public domain by showing that living arrangements especially designed for the disabled allow them to function and to retain their roles and responsibilities.

When the literature on the chronic illness experience is considered through a normalization lens, the experience is best understood in terms of the strategies that people with certain chronic conditions use in order to cope and to feel a part of society. Normalization is conceptualized as a technique for countering the effects of stigma and fitting in socially. The normalization lens portrays these people as rising above their chronic condition and its limitations to create a life that is normal for them and even inspirational for others.

The Interface of Stigma and Normalization

Examination of chronic conditions through a stigma lens involves a focus on the relationships between society and the person who is affected by the attitudinal and structural factors that characterize it. People with chronic conditions who are labelled as different or abnormal expect to be treated differently. The stigma lens provides an overview of how society treats a person with a condition at a particular point in time. It focuses on the negative and challenging social context within which a chronic illness is lived.

In contrast, examination of chronic illnesses through a normalization lens involves a focus on people's creativity, resourcefulness, and effectiveness in dealing with their physical and social limitations. While the social limitations are acknowledged, they are understood to be surmountable and manageable. Thus the two approaches examine similar phenomena from distinct angles and accord different degrees of importance to the social context and the individual's response to it.

Researchers who rely on a stigma lens to guide their analysis tend to dwell on the social attitudinal and structural factors that determine how an illness is experienced. These include: superstitions about the disease; the belief that people with chronic conditions require extra financial resources; fear of unsightly physical deformities; and the belief that people with chronic conditions are damaged, unsuitable for certain roles, or undeserving of certain privileges. The issue of stigma has a long history. In biblical times, persons with leprosy were isolated and shunned. In modern times, we use linguistic labels like "disabled" or "mentally challenged" to symbolically set certain persons apart.

Researchers who study chronic conditions through a normalization lens focus their theorizing on the various ways in which individuals with similar diseases cope and adapt. The normalization perspective values control over symptoms and the ability to make life as normal as possible. It considers the dimensions of the disease that might influence those processes as well as the emotional factors, such as self-pity, that might complicate the achievement of normalcy. For example, persons who are wheelchair-bound must accept the fact that they are in wheelchairs; although there are certain things they cannot do, they are expected to live in as normal a fashion as they possibly can.

Using one of these two perspectives as the primary analytic lens highlights either the negative social context within which an illness is lived or the positive adaptive capacity of some human beings. The theoretical orientations of our research render interaction between the two perspectives difficult to appreciate. Our monocular vision obscures the possible interdependence of stigmatization and normalization, yet we know that many of the changes in contemporary society are a direct result of consumer advocacy in relation to issues such as access and services.

It can be argued that some factors in the normalization process have great potential for social influence. Such personal qualities as coherence (Antonovsky, 1979), hardiness (Kobasa, Madding, & Kahn, 1982), and resilience (Kadner, 1989) are understood to be qualities that help people to adapt. They may also help people to turn personal experiences into political ones. The worlds of chronic illness and disability provide numerous examples of political action as an alternative to adaptation. Some forms of political activism involve peaceful change, such as lobbying for legislation that will enable those with chronic conditions to lead more normal lives. Examples of such legislation are requirements that public buildings have ramps, wide doorways to accommodate wheelchairs, elevators, wheelchair-accessible toilets, and

adapted taps. Equally relevant are structural revisions to provincial and federal human rights codes legislating equity and providing incentives for the employment of people with a visible condition. More militant approaches include a demand by parents for increased government funding so that their children with disabilities can normalize by attending mainstream classes, and a demand by HIV-positive individuals for government reimbursement of drugs that they believe will improve their quality of life, even though the drugs had not yet been tested in the usual way.

When they effect a political objective or some structural or legislative change, people with chronic conditions demonstrate that aspects of their lives deemed abnormal can be reinterpreted as normal or near-normal. For example, it is now common to see people with wheelchairs using public transport, driving cars, and performing work they could not have done a few years ago. Even fashion magazines now use models with obvious chronic conditions. As those with visible differences increase their participation in all forms of social activities, the stigmatizing force that society has exerted on them begins to erode. Thus researchers who theorize about stigma must recognize that its manifestations and conditions are evolving and dynamic. Similarly, researchers who theorize about normalization must accept the fact that stigma remains an insidious complicating factor in even the most successfully adaptive individual with a chronic illness.

Conclusion

Researchers have tended to study the experience of people with chronic conditions through either a stigma lens or a normalization lens. We have attempted to demonstrate that it may be more productive for researchers to consider people with chronic conditions as agents in the creation of a social context in which attitudes are formalized, enacted, and reframed. If we assume such a perspective, we will be able to more fully appreciate the changing social environment in which a chronic illness experience is lived, and, furthermore, will begin to see that a society's educational and legislative advances influence the lived experience of its members.

Researchers who study the experiences of people with chronic conditions only from the perspective of stigma overlook the momentum and energy in the normalization process. Those who study the experiences of people with chronic conditions only from the perspective of normalization may underestimate the power of social context and the impact that it can have on the person who suffers from a discrediting

condition. Missing from the single-lens viewpoint is recognition of the dynamic nature of the chronic illness experience and the interrelationship of stigma and normalization. We are convinced that researchers will enhance the usefulness of their theorizing if they consider the interdependence of stigma and normalization, and therefore come to truly understand the richness and complexity of the chronic illness experience. Failure to look through both lenses ensures that half of the picture will be missing.

References

Antonovsky, A. (1979). *Health, stress and coping.* San Francisco: Jossey Bass.

Brunton, K. (1997). Stigma. *Journal of Advanced Nursing, 26,* 891–898.

Charmaz, K. (1987). Struggling for a self: Identity levels of the chronically ill. In J.A. Roth & P. Conrad (Eds.), *Research in the sociology of health care: The experience and management of chronic illness* (pp. 283–321). Greenwich, CT: JAI Press.

Charmaz, K. (1991). *Good days, bad days: The self in control, illness and time.* New Brunswick, NJ: Rutgers University Press.

Cooper, R., & Burnside, I. (1996). Three years of an adult burns support group: An analysis. *Burns, 22,* 65–68.

Darling, R., & Darling, J. (1982). *Children who are different: Meeting the challenges of birth defects in society.* St. Louis: Mosby.

Davis, F. (1961). Deviance disavowal: The management of strained interaction by the visibly handicapped. *Social Problems, 9,* 120–132.

Davis, F. (1963). Passage through crisis: *Polio victims and their families.* Indianapolis: Bobbs-Merrill.

Deatrick, J., Knafl, K., & Murphy-Moore, C. (1999). Clarifying the concept of normalization. *Image: Journal of Nursing Scholarship, 31*(3), 209–214.

Fabrega, H. (1991). The culture and history of psychiatric stigma in early modern and modern Western societies: A review of recent literature. *Comprehensive Psychiatry, 32*(2), 97–119.

Frank, G. (1988). Beyond stigma: Visibility and self-empowerment of persons with congenital limb deficiencies. *Journal of Social Issues, 44*(1), 95–115.

Goffman, E. (1963). *Stigma: Notes on the management of a spoiled identity.* Englewood Cliffs, NJ: Prentice Hall.

Halm, M. (1990). Effects of support groups on anxiety of family members during critical times. *Families in Critical Care, 19,* 62–71.

Iphofen, R. (1990). Coping with a "perforated life": A case study in managing the stigma of petit mal epilepsy. *Sociology, 24,* 447–463.

Jones, E., Farina, A., Hastorf, A., Markus, H., Miller, D., & Scott. R. (1984). *Social stigma: The psychology of marked relationships.* New York: Freeman.

Kadner, K.D. (1989). Resilience: Responding to adversity. *Journal of Psychosocial Nursing, 27,* 20–25.

Katz, I. (1981). *Stigma: A social psychological analysis.* Hillsdale, NJ: Erlbaum.

Knafl, K., & Deatrick, J. (1986). How families manage chronic conditions: An analysis of the concept of normalization. *Research in Nursing and Health, 9,* 212–222.

Kobasa, S., Madding, S., & Kahn, S. (1982). Hardiness and health: A prospective study. *Journal of Personality and Social Psychology, 42,* 168–177.

Kylma, J., & Venvilainen-Julkunen, K. (1997). Hope in nursing research: A meta-analysis of the ontological and epistemological foundation of research on hope. *Journal of Advanced Nursing, 25*(2), 364–371.

Laryea, M., & Gien, L. (1993). The impact of HIV-positive diagnosis on the individual. *Clinical Nursing Research, 2,* 245–266.

Lennox, G., & Lennox, M. (1960). *Epilepsy and related disorders, Vol. 1.* Boston: Little Brown.

Macdonald, L. (1988). The experience of stigma: Living with rectal cancer. In R. Anderson & M. Bury (Eds.), *Living with chronic illness: The experience of patients and families* (pp. 177–202). Boston: Unwin Hyman.

Mechanic, D. (1995). Social dimensions of illness behavior. *Social Science and Medicine, 41*(9), 1207–1216.

Miller, J.F. (2000). *Coping with chronic illness: Overcoming powerlessness, 3rd ed.* Philadelphia: Davis.

O'Neill, D., & Kenny, E. (1998). Spirituality and chronic illness. *Image: Journal of Nursing Scholarship, 30*(3), 275–280.

Paterson, B., Thorne, S., Crawford, J., & Tarko, M. (1999). Living with diabetes as a transformational experience. *Qualitative Health Research, 9*(6), 786–802.

Phillips, M.J. (1990). Damaged goods: Oral narratives of the experience of a disability in American culture. *Social Science and Medicine, 30,* 849–857.

Royer, A. (1998). *Life with chronic illness: Social and psychological dimensions.* Westport, CT: Praeger.

Scambler, G., & Hopkins, A. (1986). Being epileptic: Coming to terms with stigma. *Sociology of Health and Illness, 8,* 26–43.

Schneider, J., & Conrad, P. (1983). *Having epilepsy: The experience and control of illness.* Philadelphia: Temple University Press.

Schwartz, C. (1957). Perspectives in deviance: Wives' definitions of their husbands' mental illness. *Psychiatry, 20,* 275–291.

Strauss, A.L., Corbin, J., Fagerhaugh, S., Glaser, B.G., Maines, D., Suczek, B., & Weiner, C.L. (1984). *Chronic illness and the quality of life, 2nd ed.* St. Louis: Mosby.

Susman, J. (1994). Disability, stigma and deviance. *Social Science and Medicine, 38,* 15–22.

Thorne, S.E. (1993). *Negotiating health care: The social context of chronic illness.* Newbury Park, CA: Sage.

Tilden, V., & Weinert, C. (1987). Social support and the chronically ill individual. *Nursing Clinics of North America, 22*(3), 613–620.

Wiener, C.L. (1975). The burden of rheumatoid arthritis. In A.L Strauss & B. Glaser (Eds.), *Chronic illness and the quality of life* (pp. 71–80). St. Louis: Mosby.

Woloshin, S., Schwartz, L.M., & Tosteson, A.N. (1997). Perceived inadequacy of tangible social support and health outcomes in patients with coronary artery disease. *Journal of General Internal Medicine, 12,* 613–618.

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