

Methods of Life-creation as Survivors of Chronic Illness —Concept Formation and the Environmental Viewpoint—

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Abstract

Individuals with chronic illness face numerous challenges, but despite their medical conditions, they exercise creativity in continuing to live everyday life. Health care providers should regard them as survivors rather than victims or patients and take a holistic view of their lives rather than focusing only on pathology or behavioral modification. However, methods for achieving this holistic approach have not yet been established. The present study proposes methods to support survivors of chronic illness from a holistic standpoint using principles of concept-formation and the environmental viewpoint. Concept-formation has mainly been applied to developing innovations in the fields of business and design. The environmental viewpoint can be used as tool to promote behavior change in survivors of chronic illness. Health care providers are encouraged to utilize concept-formation as well as the environmental viewpoint, which could be useful as a means to help survivors discover alternative ways of coping with chronic illness.

Introduction

Chronic illness is experienced on a variety of levels, from biological to social, spiritual, and psychological. For health care providers, it is important to take a holistic approach in caring for people who have chronic illness and to help them

have unique, meaningful experiences in their everyday life. The word “life” has numerous connotations and can be difficult to define. In Japanese, the term “life” can be translated as “seikatu,” “jinsei,” and “seimei” depending on the context. These terms refer to practical life, philosophical life, and biological life, respectively. While a strict definition of “life” is outside the scope of this paper, it is important to emphasize that the term “life” encompasses multiple aspects of being. Sociological studies have emphasized the interrelatedness of life and health (Sonoda & Kawata, 1995). The notion of life varies among individuals and is shaped by the environment surrounding each individual. Uniqueness, creativity, and a supportive environment are important for self-actualization and health promotion (Maslow, 1943; WHO, 1986). In line with this same trend, the term “survivor” is proposed to refer to people living with disease, especially those with psychological illness or those who have undergone traumatic experiences like abuse, war, and disaster. The term “survivor” characterizes people as having strength rather than being victims or patients (Evans & Salivan, 1995). It is useful to embrace this attitude when caring for people with chronic illness.

The present study, we proposes methods to support people with chronic illness by using

principles such as concept-formation to provide them with an opportunity to have unique life experiences, and to explore what type of environment is most conducive to this end. First, the lives of people with chronic illness and the interventions attempted by their health care providers are described. Next, the utilization of concept-formation and the environmental viewpoint are discussed.

Life with chronic illness

Chronic illness requires restructuring self and everyday life, and it necessitates giving meaning to the experience of chronic illness itself (Corbin & Strauss et.al., 1992). For example, living with diabetes mellitus requires long-term exercise and diet therapy to control blood glucose levels and prevent the development of complications. Thus, life with diabetes requires reconstructing everyday life by accustoming oneself to lifelong treatment. People with chronic illness live with complex problems and may be stigmatized or subject to moral judgments (Strauss, Corbin & Fagerhaugh, et al, 1984; Edelwich & Brodsky, 1998). Chronic illness may be accompanied by a sense of ambiguity and invisibility. On the other hand, peer group activity may give positive meaning to chronic illness (Yagi, 2005). These diverse considerations increase the complexity of problems faced by survivors of chronic illness. According to ethnographic studies, people with diabetes live in a situation of “illness but not illness” (Kondou & Ukigaya, 2004) and must therefore develop strategies to cope with illness in everyday life. As discussed above, the life of a survivor is creative and rich in diversity.

Interventions that support life-creation

Notions of disability and health develop from various conceptual models. Disease-centered or medicine-centered models focus on pathology, symptoms, and aberrations from the state of health, whereas the “social model” focuses on

holistic aspects of society and life (WHO, 2001). The relationship between health care provider and patient is not one-sided, but is rather a partnership created through interactions between both parties. Such a relationship is necessary in the creation of a life narrative (McNames, 1992).

Environment and society play a role alongside personal responsibility in contributing to individual health (WHO, 1986). When a health care provider treats a patient, it is important to address the holistic life of the survivor, including the surrounding environment, society, individual narrative, and historical context.

From an ideological framework that emphasizes the complexity of a life with chronic illness, medical intervention is viewed as a means to help the survivor discover strategies for coping with chronic illness and controlling the direction of the course of illness (Corbin & Strauss, 1992). Some researchers have explored the emergence of values such as “diversity” and “patient-centered care” in the field of healthcare (Sugimoto, 2007). Given the ambiguity and complexity of a life with chronic illness, it will be necessary to develop new methods of understanding survivors of chronic disease and to create new health policies to address their needs.

Principle of concept-formation

For people with chronic illness, life is a unique, creative, artistic process. Although the idea of concept-formation has mainly been applied to developing new concepts in business and design, it could be usefully applied to the health care domain as well. In order to generate positive attitudes about living with chronic illness, one must approach the process of life-creation from a framework that is not dominated by the notion of illness. In other words, one must engage in concept-formation. Some strategies used in concept-formation include developing associations by applying metaphor or analogy, combining widely disparate ideas and theories,

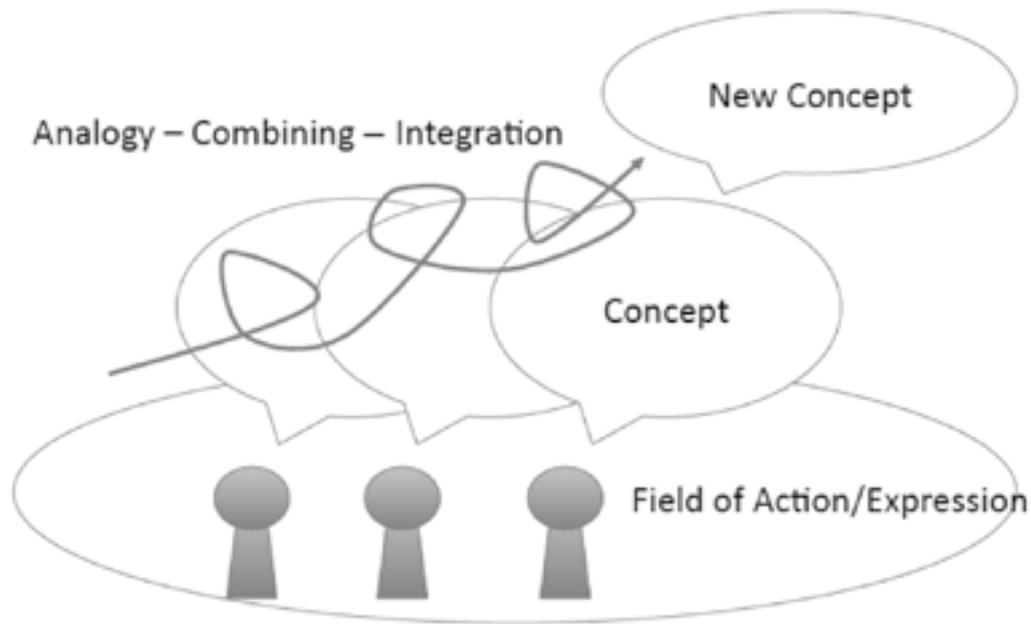


Figure 1. Concept Formation

and focusing on context and background (Nonaka & Konno, 2003; Taura, 2005). The process of concept-formation may help elucidate the ideas and mechanisms underlying one's assumptions about chronic illness.

In learning to live with chronic illness, some survivors find it useful to meet other patients with similar conditions in order to compare life experiences and share coping strategies. In these situations, some survivors may share similar conceptual frameworks, while others may have different conceptual frameworks. Survivors interact together, and during this process old concepts are analogized, combined, and integrated into a new concept (Figure 1). This process contributes to expanding notions of living with chronic illness and may generate alternative ideas about how to live everyday life. This process, which may help unlock the personal potential of survivors of chronic illness and empower them to confront their illness, is vital factor in recovering from illness, promoting health, and increasing health education (Anderson, Funnell and Anderson et.al., 2003;

WHO, 1986; Herman, 1992). It is said that, in the process of reflecting on the experience of illness and recovery, survivors generate a "new self" (Herman, 1992). Concept-formation could be one method for generating such a "new self." The method of concept-formation, which involves a deliberate analysis of the effect of illness on the survivor's life, may help craft a new self-image for the survivor, one that differs from the stereotype of the patient as merely ill. Such a discovery process may provide the survivor with a new role as the creator of his or her own life.

But concept-formation as described above is only one of several frameworks that have the potential to explain the life-creating process and to develop strategies for assisting survivors of chronic illness. It will be necessary to further explore these theoretical frameworks.

Role of environment

Concept-formation focuses mainly on the individual's role in life-creation. The environmental viewpoint is a broader approach to assist survivors. Survivors of chronic illness are

required to alter many aspects of everyday life, such as diet, exercise, and other social behavior. For this reason, providers often take an educational approach to encourage changes in health behavior. However, the educational approach is limited in its ability to achieve long-term behavioral change. In addition, this approach may result in feelings of guilt in the survivor over having failed to achieve behavioral change. Since it is impossible to separate the acts of an individual from the surrounding environment, behavioral modification must be considered in the context of the relationship between individual and environment.

Although there are many approaches to consider the relationship between survivor and environment, this chapter discusses the environmental approach using the principle of “affordance.” Affordance refers to the fact that characteristics of an object induce some desired action (Sasaki et al., 2006). For instance, the design of a door knob is conducive to the turning action, and the design of a mug handle induces a grasping action. The value of design depends on its naturalness. The ideal design of an object features characteristics such that the function of the object emerges naturally without any particular emphasis upon its purpose. In other words, an excellent design is one that does not call attention to the relationship between the object and its human user (Igarashi, Umemura, and Ohtsubo et al., 2007). Object design is based upon some intended action, but excellent design does not assert intention. Although this principle is based on the example of object design, it can be applied to the care of survivors of chronic illness. Traditionally, a health educator expects the patient to institute behavioral change. For this reason, interventions may be based on behavioral change theories such as the trans-theoretical model or locus of control model (Prochaska & Velicer, 1997; Peyrot & Rubin, 1994). Such interventions can be successful in effecting

behavioral change. But this type of intervention relies on the patient being aware of the underlying behavior at the root of the problem. Discussing the relationship between the environment and individual actor using the principle of affordance could present an alternative way to educate patients. This method may avoid some of the pitfalls of traditional educational intervention; in particular, it may prevent the survivor from feeling guilty for failing to achieve a behavioral change.

In the same way, the discussion of environmental influence helps reshape not only the notion of behavioral change, but also other aspects of the health care system such as routine health checkups. The system of routine health checkups is based on a strict set of clinical values that have been established to prevent the development of disease by encouraging early intervention by health care providers and patients. This is an important goal, but as the Health Promotion Law indicates, it depends on patients having a heightened awareness of their own health. In order to realize this end, health policy should help construct an environment that allows people to be health-conscious by the principle of affordance. The individual and environment are not independent entities. As all behavior occurs within an environment, the boundary between individual and environment is ambiguous (Drengson & Inoue, 1995). Actions in everyday life are suited to the situation at hand, and this situation-dependent behavior is frequently repeated. Through these processes, behavior becomes somatized (Bourdieu, 1979). This fact highlights the importance of considering the effect of environment when attempting behavioral formulation. The notion of affordance assumes that there are inherent individual meanings and values in the environment, and for this reason affordance can have an impact beyond its role in promoting behavioral change.

Behavior modification for survivors of chronic

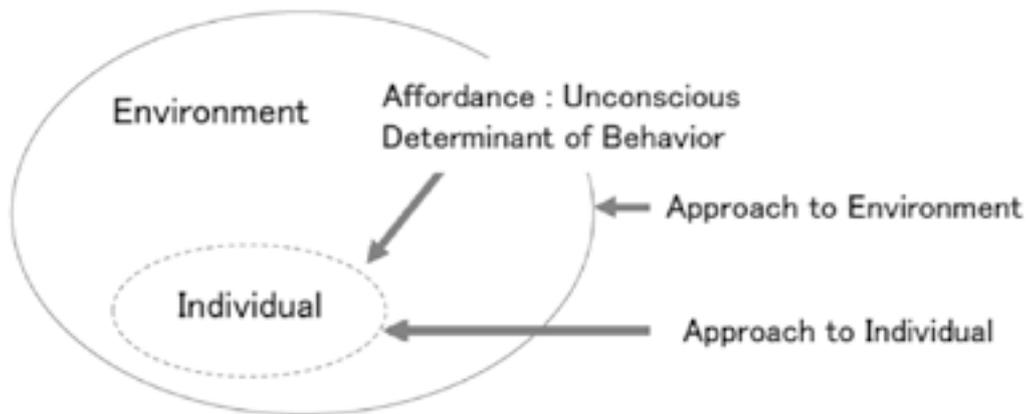


Figure 2. Relationship between individual and environment

illness may depend as much on the surrounding environment as on any individual choice. Because of this, health care providers engaging in patient education should take a comprehensive, holistic view of life with chronic illness and bear in mind the interrelatedness of individual and environment (Figure 2).

Finally, in addition to struggling with behavioral change, survivors may experience social and psychological difficulties. For this reason, health care providers should explore the possibility of designing an environment that minimizes the exposure of survivors to prejudice and stigma.

Conclusion: Survivor life-creation and the role of health care providers

Concept-formation and the environmental viewpoint are critical in supporting the process of life-creation for survivors of chronic illness. Here, concept-formation was explored as one means of assisting survivors of chronic illness. In addition, the effect of environment on individual behavior is discussed, and the importance of the environmental viewpoint when trying to effect behavioral change is emphasized. Ideally, environment should be constructed in such a way that one is not aware of its intended effect. Finally, the limitations of attempting behavioral

change without considering the link between individual and environment are highlighted.

Survivors of chronic illness exercise creativity in the process of coping with chronic illness and finding meaning within everyday life. Individuals differ in their degree of sensitivity towards their situation. What is a minor or unimportant circumstance for one person may have major impact for another person (Anderson, Funnell & Anderson, 2003). In addition, many survivors spend a great deal of energy attempting to lead ordinary lives. Their struggle, though it permeates their lives, may go unrecognized. Facing numerous daily challenges, survivors live in a world where there is no clear solution to their problems. Survivors engage their environment and attempt to overcome their difficulties via trial and error. Through these processes, survivors construct new concepts, develop new strategies for coping with everyday life, and discover new meanings in their lives. Programs directed towards health promotion or patient education must embrace the holistic perspective and consider the relationship between individual and environment when working towards behavioral change. Much work remains to delineate the relationship between concept-formation and the environmental viewpoint.

Health care providers should not attempt to

control the patient, but should maintain a neutral stance. Health care providers should value the patient's self-determination and should not try to dictate life choices to the patient. The relationship between patient and health care provider is only one of many relationships in the life of a survivor of chronic illness (Herman, 1992). As many diseases have a chronic nature and illness takes on multiple meanings, health care providers have an increasingly limited role in the life of the patient. Therefore, it is important to continue to reflect upon the complex and ever-evolving relationship between patient and health care provider. Concept-formation and the environmental viewpoint are tools that can be used to improve relationships between patients and health care providers. But these viewpoints comprise only a small fraction of the many approaches that can be taken to facilitate holistic life-creation. Future studies will hopefully include an exhaustive theoretical discussion of concept-formation and the environmental viewpoint, based on the reflection of the everyday life of a survivor of chronic illness. In addition, the role of health care providers in individual life-creation, as well as establishing methodology to create individual life experiences and a supportive environment is necessary.

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