ORIGINAL RESEARCH

Understanding stigma in chronic health conditions: Implications for nursing

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Abstract

Purpose: This article explores the social processes in stigmatization and the theoretical background on the impact in chronic illness.
Data sources: Review of literature from social sciences and applications to health issues.
Conclusions: Understanding the social utility of stigmatization in preserving social cohesion and protecting the social order is an important function. However, this process can be harmful when applied to persons with chronic illness, such as HIV-AIDS, and psychiatric illness. These individuals often become shamed, ostracized, isolated, discredited, and socially and economically marginalized. Recent theoretical work on stigma has identified several issues and patient responses that may have implications in many other chronic conditions. Stigma is based on visible or nonvisible health conditions and can be both externally imposed or perceived in a process of self-stigma.
Implications for practice: Understanding stigma can aid clinicians in providing supportive help for patients with chronic illness. Stigma has been well researched in a few chronic illnesses; however, future studies in other conditions are much needed. Recognizing the underlying social factors has potential use in health-promoting behaviors. Sensitivity to stigma allows health professionals to critically reflect on ways the healthcare environment may add to stigma for their patients.

Stigma is a factor in many chronic health conditions. While many are familiar with the issues of stigma in mental health issues or HIV/AIDS, research continues to be conducted regarding stigma in many other chronic conditions. It is important for nurses to understand the universality of stigma and the social functions that are related to this process. This article focuses on the social functions of stigmatization and the theoretical work regarding the impact of health-related stigma on individuals and groups and the implications for chronic health conditions.

Stigma is a form of social labeling, which affects one's social identity. Generally, stigma or having a stigmatized condition is a mark of shame and discredits the individual as deviant, undesirable, unworthy, or even dangerous. Stigma is a social process of marking an individual as deviant and is often associated with an inability to fulfill a social role. The stigmatized individual suffers altered identity, shame, associated blame for the stigma, and often lowered self-esteem. The components include labeling, stereotyping, and discrimination, which are associated with status loss (Link & Phelan, 2001). This process leads to categorizing, marginalization, or even ostracization, which isolates the individual from full participation in society. Stigmatization has been well explored in areas of health such as HIV-AIDS, disabilities, substance abuse, and mental illness. More recent work is emerging regarding the importance of stigma in other chronic conditions. It is important to understand the historical aspects of stigma, current research from sociology, and psychology to better understand how stigma develops. Additional research from psychology has explored the individual's response to being stigmatized for a chronic health condition. An understanding of stigma and how it affects patients is relevant to nurse clinicians and researchers.

The word stigma comes from a practice in ancient Greece in which tattoos were used to identify criminals, slaves, and traitors. Historical examples include the "Mark of Cain" from the Biblical book of Genesis in

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which Cain, who murdered his brother, had a mark or sign placed on him to warn others that killing Cain would provoke the vengeance of God. People with leprosy were often ostracized and separated from society and the word "leper" has come to have a connotation of separation even in modern times. Many social and religious practices and rituals have a protective element. Throughout history, illness and deviant behavior have been given social labels and often these people have been ostracized.

Anthropological and sociological perspectives on the function of stigma in social structure

The process of stigmatization is a universal aspect of the human condition and can support group cohesion and the protection of that group. E. O. Wilson (1998) postulated that forming social connection is part of our sociobiology. Social animals are designed in such a way that the survival of the individual depends on the other members of the group. As social animals, humans depend on each other for food and to defend themselves. Social rules and norms are a way of establishing order in the social structure and control external boundaries of the social group. Thus, as social animals, our social bonds are crucial to our safety and well-being. The human tendency is to form groups, identify with them, and classify others who are not part of the group. Durkheim described these social classifications as including an identification of those who are deviant and a threat to the social order and establishing boundaries that create a collective sense of identity and morality (as cited in Moore, 2009).

Social groupings may be organized along kinship or tribal lines or other factors, such as religious or political leanings, or other commonalities. Identification with a group leads to increased comfort with other members of the group. For example, a group of nurses may draw boundaries around the group as "us" and other professionals, such as lawyers and physicians as "them."

Wittgenstein (1957) noted the importance of perpetuating social values of honorable upright behavior and appearance as a staple of sociability, which is possible only if a breach of the norms is publically marked. Durkheim also maintained that what is normal and acceptable behavior is in part defined by contrasting it with that, which is abnormal/unacceptable (as cited in Applerouth & Edles, 2008). Adherence to the normal is important for collective solidarity and is necessary for the functioning of the social group. Anyone feeling cut off from their group will naturally be in a state of high anxiety. The threat of social alienation causes people to behave according to social norms. These norms are very powerful and lead to group cohesion, conformity, and may be protective of its members, and establishing order in the social structure.

Anthropologist Mary Douglas (1984), while studying group behavior across cultures, examined the issues of taboos in the classic book, *Purity and Danger*. Danger or harm comes from impurity, disorder, dirt, or matter out of place. Anomalies, deviances, or deviant behavior are ambiguous and therefore threaten the natural order. Classification systems of deviancies are inherent in human thinking and social organization. Taboos are coding processes that identify and manage disorders that threaten dangers if the code is broken, and therefore are protective for the group. For example, dirt is matter out of place, which constitutes danger, and illness or dysfunction is a sign of disorder. Taboos are set up to protect the group and enforce the consensus on the way the world is organized, thereby reducing social disorder, cognitive discomfort, and ambiguity. Feared contagion extended the danger of a broken taboo to the broader community. Social groups approach these ambiguities or disorder by establishing order through rules. Often these rules are based on avoidance and include separation, demarcation, and awareness of the dangers of crossing forbidden boundaries. Stigmatization is one way of separating an individual who is deviant or anomalous; hence, a threat to the social order. Rituals are often employed to avoid harm, to purify, or cleanse to assure safety.

Social identity is generally based on physical appearance and behavior, professional roles, and concept of self. Goffman's (1963) classic work described stigma as a process in which one's normal identity is spoiled by the reaction of others. Stigma is a gap between virtual social and actual social identity. This can disqualify a person from full social acceptance and is a mark or sign that is socially discrediting. Goffman classified stigma as discrediting via visual cues (obvious appearance and/or behavior) and discreditable (nonvisible diseases, nonobvious but existent). Three types of stigma were identified by Goffman: (a) physical deformity such as aging or disease; (b) character blemish such as homosexuality, drug abuse (this may evoke a moral judgment as the person is deemed responsible for the condition); and (c) prejudice as a "tribal" form of stigma related to race religion or class. Physical deformity includes aging or overt deformities, scars, leprosy, or a physical disability. Personal traits such as behaviors related to mental illness, addictions, criminal backgrounds, etc., are also sources of stigma reflecting a character blemish. Ethnic groups, members of a different religion, or social class are seen as a form of "tribal stigma," which labels persons from different backgrounds as "other."

Health-related stigma and social constructions of illness

From a social constructionist perspective, meaning and values are shaped by cultural and social systems (Conrad & Barker, 2010). Despite the labeling of a chronic condition as a disease, social and cultural meanings are still attached and certain diseases have negative connotations. Thus, while there is nothing dangerous or socially deviant inherent in the condition, a social response to the disease and the manifestations may lead to stigmatization. Medical conditions have historically been subject to stigmatization through social models. In contemporary society, it is important to differentiate between medical models of pathology associated with a disease diagnosis and a social model, which is based on the limitations of opportunities to participate in society because of barriers imposed by society. Conrad and Barker (2010) cited research on many stigmatized illnesses, such as leprosy, epilepsy, cancer, mental illness, HIV/AIDS, sexually transmitted diseases, etc. As stigma is a social construct, the meanings change across cultures or over time. For example, epilepsy has been viewed alternatively as demon possession, a brain disorder, or as a spiritual gift as described in Fadiman's (1997) book *The Spirit Catches You and You Fall Down*.

Talcott Parsons (1951), a structural-functionalist oriented sociologist, described the "sick role" as having the following components: (a) exemption from normal social roles and responsibility for causing the condition; and (b) an obligation to want to get well and to adhere to medical recommendations. This allowed for a medical diagnosis to remove the moral stigma of causing the deviancy as a character deviancy. Peter Conrad (2007) also described the medical institutional control of such deviance by labeling it an illness rather than deviant behavior. He also cautioned about the medicalization of normal human behavior and life transitions.

Theoretical models of stigma related to health issues

The dimensions of stigma include visibility, controllability, course and perceived danger, and enacted or perceived stigma (Green, 2009). Aesthetics, disruptiveness, and concealability are related to the degree in which the deviance is obvious and visible. Some chronic conditions are discredited by having a visible condition, such as dwarfism or physical deformities, and are contrasted with more "hidden" conditions such as an undisclosed illness as diabetes, in which an individual can "pass as normal." However, these individuals often live with the fear that others will find out and subsequently discredit them. Controllability refers to the association with deviant behavior. For example, persons with HIV/AIDS were seen as blameworthy for their condition. The course of the illness may also be a factor as some illnesses become more pronounced over time and others pose a risk of contagion. Green (2009) makes a distinction between stigma that is enacted, in which actual sanctions are applied, and perceived stigma, in which the individual has feelings of shame and oppression.

Social psychology perspectives on responses to stigmatization

Much stigma research has been conducted on mental illness and the historical issues of lumping mental illness with criminal and deviant behavior (Sadler, 2009). More recently, a process of internalizing stigma or "self-stigma," as distinguished from public stigma, has been studied extensively, particularly among persons with mental illnesses (Watson, Corrigan, & Larson, 2007). Both begin with a stereotype regarding a negative belief about a group. This leads to prejudice or agreement with the stereotype, such as anger and fear (public) and low self-esteem and self-efficacy (self). This can culminate in discrimination: avoidance of work and other opportunities (public) and failure to pursue work or other opportunities (self). Watson, Corrigan, Larson, and Sells (2007) developed a model of the internalization of stigma based on group identification and legitimacy. This begins with stigma awareness and the individual endorsement of the public stereotype, and self-concurrence results in low self-esteem and self-efficacy. Corrigan, Rafacz, and Rusch (2011) have researched a four-stage progressive model of self-stigma leading to diminished self-esteem and hope: (a) being aware of the stereotype; (b) agreeing with the negative stereotype; (c) applying it to oneself; and (d) suffering lower self-esteem. Corrigan and Watson (2002) have written extensively on the harmful effects of stigma on self-esteem and self-efficacy; but have also noted that some people are energized by prejudice and express righteous anger while others seemingly ignore public prejudice altogether.

Conrad and Schneider (1992) researched people with epilepsy, finding a typology of modes of adjustment. Three categories included (a) the pragmatic type who attempted to pass or cover, only disclosing their diagnosis selectively; (b) the "secret" type who use elaborate tactics to conceal their disease; and (c) a "quasi-liberated" type who publically proclaimed their epilepsy to educate others. Scrambler (2009) reported on a "hidden distress model of epilepsy," which described the shame and fear of encountering enacted stigma. This entailed a strong sense of felt stigma predisposing them to secrecy and concealment.

Labeling theory

Social psychologists Link and Phelan (2001) conceptualized a model of stigma that included labeling, stereotyping, separation, status loss, and discrimination. They also describe the exercise of social power over the stigmatized. Labels are generally taken for granted and are often based on substantial oversimplification to create groups and differ from time and place. They suggest using the word "label," rather than "mark." They cite evidence of separation or isolation, through labeling persons from having a disease as being the disease, that is, one with epilepsy or schizophrenia is seen as an epileptic or schizophrenic. In a widely cited conceptual model, they conceptualized stigma as the co-occurrence of the following components: labeling, stereotyping, separation, and emotional reactions. These often result in status loss and discrimination. They conclude that the concept stigma has relevancy for multiple conditions and impacts the lives of those stigmatized including diminishing life earnings, housing, health, and life itself.

Green (2009), in writing on response to labeling, noted that labels can be assigned from behavior, appearance, and even from medical diagnoses. Sometimes the anticipation of this medical labeling of disease may constitute a barrier to seeking treatment. Additionally, the labeled person may internalize the identity and behavior, thereby becoming more consistent with the label. Stereotyping involves a connection to categorize one who has the label. This is often automatic and explained as "cognitive efficiency." The third feature is separating "us" from "them" or "othering." People who are stigmatized are seen as embodying ambivalent, dangerous, polluting, and contaminating characteristics, which frighten other people. Frequently, there is a downward placement on the social hierarchy, with a loss of power and social status, which may include disadvantage in income, well-being, and health. Individual and institutionalized discrimination frequently follow.

Stigma and chronic illness

Scrambler (2009) explored stigma in chronic illness. Chronic illness has been described as "biological disruption," "loss of self" in which lives are threatened by "impairment (body deficit)," "disability (functional loss)," or "handicap (social cost)" (p. 444). Stigma in HIV-AIDS has been studied and introduces an additional related feature of "felt normative stigma" and "internalized stigma." There was a negative association between the disease and behavior in the perspective of the public, so stigma took on a related concept of deviance. Scrambler (2009) differentiates between stigma and deviance. Stigma relates to a deficit or imperfection, that when internalized leads to shame; while deviance suggests a moral deficit or immoral behavior, that when internalized leads to blame. In some cases this public perception of shame and blame has been used to socially change risky health behaviors, such as an emergent stigma attached to smoking. Mobilizing stigma and creating risky health behaviors as deviant may be a way of harnessing the concept of stigma for better health.

Conrad and Barker (2010) described two other contemporary models: contested illness and disability empowerment. Contested illness includes those in which the sufferer claims to have a disease that many physicians do not acknowledge as distinctly medical because they present without any known physical abnormality, such as chronic fatigue, irritable bowel, and fibromyalgia. These conditions are medically invisible in an era of highly technologized medicine (Dumit, 2006). In the case of disabilities, impairment is redefined: instead of a personal tragedy (following medically determined standards of normality), the condition becomes politicized. According to Green (2009), this moves from a social position of oppression, dependency, and helplessness into a movement in which those with disabilities have organized and mobilized from oppression to empowerment and have changed infrastructures and services to limit the obstacles that limit opportunities for social participation.

Social ecological perspectives

More recently, some literature has shifted from a focus on the individual stigmatized person to an ecological model that situates the individual in different levels of social life (Pescosolido, Martin, Lang, & Olafsdottir, 2008). This perspective sets the normative expectations involved in the process of stigmatization and locates the psychological and individual factors at the micro or local level. Next, the meso level includes social networks or organizational factors and finally, the macro or societal-wide factors. Some theories have incorporated a critical theories approach, focusing on power and social oppression. These theories explore economic, social, and political structures and examine how social power structures restrict opportunities and low social value. Link, Phalen, and Dovidio (2008) have also examined the concepts of stigma and prejudice. Green (2009) noted that these power structures permeate all social organizations, including the medical and caring professions. Providing care and treatment that encourages the recipient to be dependent and helpless may contribute to this oppression. The examples of the movement against this dependence by many in the disabled community are a testimony to social action in which environments have been altered to

accommodate people with disabilities. Additionally, this group has used social organization to change public policies to guarantee more opportunities that can accommodate their restrictions, rather than promote dependency.

Another focus has emerged on the morality of social structural discrimination in which social and economic powers have been incorporated into stigmatized conditions cross culturally (Yang et al., 2007). Some of these models examine how stigma predisposes individuals to poor outcomes. Labeling theory posits that expectations of devaluation occur with the official labeling of a medical diagnosis and treatment, especially in mental illness. Social marginalization then limits social roles and other opportunities. Kleinman (1995) and Kleinman, Das, and Lock (1997) identified stigma as a moral experience that deals with everyday life and engagement, thereby confounding social suffering. Stigma is a universal phenomenon and is evident across cultures. One example is how mental illness in China assigns a moral defect to the entire family in "loss of face." In the United States, with values of individualism, individual initiative, and freedom, persons with mental illness or other chronic illness may be denied opportunities in education and occupation and then characterized as underserving of social welfare benefits related to their limitations to work and become successful. Stigma thus spans physical-emotional-social-cultural domains and threatens what matters in people's lives (Kleinman & Hall-Clifford, 2009).

Nursing perspective

The issue of stigma in patient populations is vital to nurses who care for the person and how they live with chronic conditions. Joachim and Acorn (2000b) conducted a meta-study on qualitative research and subsequently developed a theoretical framework on stigma. They focused on chronic conditions classified as visible and invisible. Responses to visible conditions, such as an alteration of physical appearance, were of covering or alternatively, an automatic disclosure in which they responded to the discreditation by being truly unconcerned or behaving as if it were unimportant. This had the sequelae of disregarding the pain, isolation, and challenging, or covering in the future. Three responses to invisible conditions included prevent disclosure, nondisclosure, or protective disclosure. Disclosure can either result in support or stigma resulting in rejection, isolation, and stress. Nondisclosure may result in passing for normal and becoming part of the group and/or feeling stressed. Passing for normal can sometimes result in being caught in a lie, leading to discreditation and stress. The final option is preventive disclosure that is used in cases of an invisible condition that is not under an individual's control such as epilepsy. In these cases the individual may selectively disclose so others will be prepared to help and may conceal on a more general level.

Joachim and Acorn (2000a) also found that most reports on stigma reported the experience through a lens of the stigma experience or normalization, and rarely both together. The stigma focus explores the manner in which the individual suffers from the stigma. The normalization lens focuses on the ways in which the individual achieve normalcy. The later approach describes efforts of the individuals to "fit in," an attempt to create a positive attitude toward living with chronic illness. The processes of normalization include developing coping abilities, concealment, maintaining a positive self-image. A process of "supernormalizing" or achieving an excellent state of health, using spirituality as a way of maintaining a sense of well-being, was described.

Conclusions and summary

Stigmatization is a universal human behavior that promotes group cohesion and safety. Stigma is often a part of the patient experience in chronic health conditions. This can occur in visible and invisible heath disorders. In addition to the stigmatization of others, patients often internalize the stereotype. This labeling may result in stereotyping, separation and isolation, lack of social status, and discrimination.

Clinical and research implications

An understanding of the social and individual issues in stigma has implications for social policy, ethics, and clinical awareness and understanding. While stigma has been well studied in some areas, such as HIV/AIDS and mental illness, more research in other chronic health conditions is warranted. A better understanding of the issues and patient experiences with stigma are important to all nurses in clinical practice. Healthcare providers are not exempt from many of these social constructions that formulate stigma, so self-awareness and understanding are extremely important. Additionally, understating the patient experience of stigma may be helpful in providing care to those patients with chronic conditions. Research exploring how patients with other chronic conditions experience stigma in everyday life has implications for clinical practice. Provider sensitivity to how patients navigate everyday life and manage stigma may also be informative for good nursing care.

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