

CHAPTER 3

Stigma

My car came to a stop at the intersection. I looked around me at all the people in the other cars, but no one there was like me. They were apart from me, distant, different. If they looked at me, they couldn't see my defect. But if they knew, they would turn away. I am separate and different from everybody that I can see in every direction as far as I can see. And it will never be the same again.

—Client with new diagnosis of cancer

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INTRODUCTION

This chapter demonstrates how the concept of stigma has evolved and is a significant factor in many chronic illnesses and disabilities. It also explores the relationship of stigma to the concepts of prejudice, stereotyping, and labeling. Because stigma is socially constructed, it varies from setting to setting. In addition, individuals and groups react differently to the stigmatizing process. Those reactions must be taken into consideration when planning strategies to improve the quality of life for individuals with chronic illnesses.

Although stigmatizing is common, not all individuals attach a stigma to their disease or disability. This chapter does not assume that all who come in contact with those who are disabled or chronically ill devalue them; rather, it insists that each of us examine our values, beliefs, and actions carefully.

Merriam Webster (2011a) defines stigma as a “mark of shame or discredit, an identifying mark or characteristic,” and as a “mark of guilt

or disgrace” (2011b). Goffman (1963) traced the historic use of the word stigma to the Greeks, who referred to “bodily signs designed to expose something unusual and bad about the moral status of the signifier” (p. 1). These signs were cut or burned into a person’s body as an indication of being a slave, a criminal, or a traitor. Notice the moral and judgmental nature of these stigmas. The disgrace and shame of the stigma became more important than the bodily evidence of it. Labeling, stereotyping, separation, status loss, and discrimination can all occur at the same time and are considered components of the stigma (Link & Phelan, 2001).

THEORETICAL FRAMEWORKS: STIGMA, SOCIAL IDENTITY, AND LABELING THEORY

Society teaches its members to categorize persons by common defining attributes and characteristics (Goffman, 1963). Daily routines establish the usual and the expected. When we

meet strangers, certain appearances help us anticipate what Goffman called “social identity.” This identity includes personal attributes, such as competence, as well as structural ones, such as occupation. For example, university students usually tolerate some eccentricities in their professors, but stuttering, physical handicaps, or diseases may bestow a social identity of incompetence. Although this identity is not based on actuality, it may be stigmatizing.

One’s social identity may include: 1) physical activities, 2) professional roles, and 3) the concept of self. Anything that changes one of these, such as a disability, changes the individual’s identity and, therefore, potentially creates a stigma (Markowitz, 1998). Goffman (1963) used the idea of social identity to expand previous work done on stigma. His theory defined stigma as something that disqualifies an individual from full social acceptance. Goffman argued that social identity is a primary force in the development of stigma, because the identity that a person conveys categorizes that person. Social settings and routines tell us which categories to anticipate. Therefore, when individuals fail to meet expectations because of attributes that are different and/or undesirable, they are reduced from accepted people to discounted ones—that is, they are stigmatized.

Goffman recognized that people who had stayed in a psychiatric institute or a prison were labeled. To label a person as different or deviant by powers of the society is applying a stigma (Goffman, 1963). In general, labeling theory is the way that society labels behaviors that do not conform to the norm. For instance, an individual experiencing constant drooling or the leakage of food that requires frequent wiping of the mouth exhibits behaviors different from the norm. The difficulty in swallowing may be labeled by

society as deviant behavior, despite the fact that tremor and dyskinesias associated with Parkinson’s disease may be the cause (Miller, Noble, Jones, & Burn, 2006). Therefore, the concept of deviance versus normality is a social construct. That is, individuals are devalued because they display attributes that some call deviant (Kurzban & Leary, 2001).

During the 2 decades following Goffman’s work in the 1960s, extensive criticism arose concerning the impact and long-term consequences of stigma on social identity. In the area of mental illness, critics resisted the theory that stigma could contribute to the severity and chronicity of mental illness. In a series of studies, Link proposed a modified labeling theory that asserted that labeling, derived from negative social beliefs about behavior, could lead to devaluation and discrimination. Ultimately, these feelings of devaluation and discrimination could lead to negative social consequences (Link, 1987; Link et al., 1989; Link et al., 1997). Those who are labeled with mental illness often are excluded from social activities and discriminated against when they do participate.

In 1987, Link compared the expectations of discrimination and devaluation and the severity of demoralization among clients with newly diagnosed mental illness, repeat clients with mental illness, former clients with mental illness, and community residents (Link, 1987). He found that both new and repeat clients with mental illness scored higher on measures of demoralization and discrimination than community residents and former clients with mental illness. Further, he demonstrated that high scores were related to income loss and unemployment.

In 1989, Link and colleagues tested a modified labeling theory on a similar group of clients with newly diagnosed mental illness,

repeat clients with mental illness, former clients, untreated clients, and community residents who were well (Link et al., 1989). They found that all groups expected clients to be devalued and discriminated against. They also found that, among current clients, the expectation of devaluation and discrimination promoted coping mechanisms of secrecy and withdrawal. Such coping mechanisms have a strong effect on social networks, reducing the size of those networks to persons considered to be safe and trustworthy.

In 1997, Link and colleagues tested modified labeling theory in a longitudinal study that compared the effects of stigma on the well-being of clients who had mental illness and a pattern of substance abuse to determine the strength of the long-term negative effects of stigma and whether the effects of treatment have counterbalancing positive effects (Link et al., 1997). They found that perceived devaluation and discrimination, as well as actual reports of discrimination, continued to have negative effects on clients even though clients were improved and had responded well to treatment. They concluded that healthcare professionals attempting to improve quality of life for clients with mental illness must contend initially with the effects of stigma in its own right to be successful.

Fife and Wright (2000) studied stigma using modified labeling theory as a framework in individuals with HIV/AIDS and cancer. They found that stigma had a significant influence on the lives of persons with HIV/AIDS and with cancer. However, they also found that the nature of the illness had few direct effects on self-perception, whereas the effects on self appeared to relate directly to the perception of stigma. Their findings suggested that stigma has

different dimensions, which have different effects on self. Rejection and social isolation lead to diminished self-esteem. Social isolation influences body image. A lack of sense of personal control stems from social isolation and financial insecurity. Social isolation appears to be the only dimension of stigma that affects each component of self.

Camp, Finlay, and Lyons (2002) questioned the inevitability of the effects of stigma on self based on the hypothesis that, in order for stigma to exert a negative influence on self-concept, the individuals must first be aware of and accept the negative self-perceptions, accept that the identity relates to them, and then apply the negative perceptions to themselves. A study of women with long-term mental health problems found that these women did not accept negative social perceptions as relevant to them. Rather, they attributed the negative perceptions to deficiencies among those who stigmatized them. These researchers found no evidence of the passive acceptance of labels and negative identities. These women appeared to avoid social interactions where they anticipated feeling different and excluded, and formed new social networks with groups in which they felt accepted and understood. Whereas they acknowledged the negative consequences of mental illness, there did not appear to be an automatic link between these consequences and negative self-evaluation. Factors that contributed to a positive self-evaluation included membership in a supportive in-group, finding themselves in a more favorable circumstance than others with the same problems, and sharing experiences with others who had knowledge and insight about mental illness.

In summary, stigma, defined as discrediting another, arises from widely held social

beliefs about personality, behavior, and illness, and is communicated to individuals through a process of socialization. When individuals display the condition that engenders the mark of discredit, they may experience social devaluation and discrimination. Stigma clearly attaches to individuals with mental illness as well as individuals with infectious and terminal diseases. Stigma may produce changes in perception of body image, social isolation, rejection, loss of status, and perceived lack of personal control. However, there is some evidence to suggest that stigma does not attach universally to individuals with marked behavior or conditions. Some individuals appear resistant to stigma, identifying flaws in the society conveying the negative beliefs. These individuals share experiences with others who have knowledge of and sensitivity to being stigmatized and benefit from the ability to perceive themselves as equal to or better off than others with the same condition.

Unique Aspects of Stigma

There are special circumstances in which stigma can be perceived with enhanced distinction. Individuals who lack a fully developed sense of personal identity and who are reliant upon external sources to reinforce their internal sense of worthiness may be uniquely prone to a sense of stigma. Adolescence can be used as an example. There are aspects of society that tend to be highly valued by individuals, and when that society communicates stigma, the stigmatizing beliefs are uniquely powerful. Religion and culture are examples, as well as issues concerning self-infliction and punishment.

The task of developing a stable, coherent identity is one of the most important tasks of adolescence (Erikson, 1968). To successfully

complete this task, the adolescent must be able to utilize formal operational thinking within a context of expanded social experiences to evolve a sense of self that integrates not only the similarities, but also the differences observed between the self and others. Social interactions and messages from the sociocultural environment about what is desirable and what is not desirable guide and direct the adolescent toward an identity that incorporates desired similarities and rejects undesired differences. The influences and preferences of peers become important as the adolescent seeks acceptance of this newly developed sense of identity. The skill of labeling and stigmatizing individuals with intolerable differences is wielded with frightening force and sometimes terrible consequences—the 1999 Columbine High School tragedy is one example.

Intolerance often results in bullying and peer aggressiveness in the adolescent. Wang, Iannotti, Luk, and Nansel (2010) examined subtypes of bullying in a national sample of 7,475 adolescents in the United States. Bullying of all types (verbal, physical, relational, cyber, and cell phone) that occurred among students in grades 6 to 10 was related to depression, physical injuries, and increased medication use to manage nervousness and insomnia. Bullying, including cyberbullying, has also been linked to suicidal thoughts and behaviors in the adolescent (Brunstein Klomek, Sourander, & Gould, 2010; Hinduja & Patchin, 2010).

Normal adolescent maturation may include dealing with sudden growth spurts, changes in body image, and even acne associated with fluctuating hormone levels. Australian researchers (Magin, Adams, Heading, Pond, & Smith, 2006) explored the experience of adolescents living with very visible skin disorders (e.g., severe acne, psoriasis). These youth (aged 11–18 years)

were stigmatized and frequently were the targets of teasing and bullying behaviors by peers.

Culture may determine stigma as well. For some conditions, such as traumatic brain injury (Simpson, Mohr, & Redman, 2000), HIV/AIDS (Heckman et al., 2004), and epilepsy (Baker, Brooks, Buck, & Jacoby, 2000), stigma and social isolation cross cultural boundaries. On the other hand, in a study of attitudes about homelessness in 11 European cities, Brandon, Khoo, Maglajlie, and Abuel-Ealeh (2000) found marked differences in attitudes between countries, with high levels of stigma predominating in former Warsaw Pact countries. A determination of racial and/or cultural inferiority of a minority group by a dominant group may result in racism, discrimination, and stigma (Weston, 2003).

Religion may also play a role in stigma. In a study of five large religious groups in London that examined attitudes about depression and schizophrenia, it was found that fear of stigma among nonwhite groups was prevalent, and particularly the fear of being misunderstood by white healthcare professionals not of the same religious group (Cinnirella & Loewenthal, 1999).

The label and associated stigma of a disability or disease excludes individuals from social interaction or alters social relationships whereas their intellectual or physical handicaps alone may not (Link et al., 1997). Vulnerable populations are in jeopardy of forming unhealthy relationships. Results from a South African study (Rohleder, 2010) indicated that the stigma of disability increased participation in risky behaviors. Individuals with a physical or mental disability were more likely to engage in unsafe sexual practices, thereby increasing their risk of contracting HIV/AIDS. The desire to form an attachment and establish a physical relationship with another human being

outweighed the need to protect oneself. The concepts of self-worth and self-esteem are interwoven with stigma.

Most stigmas are perceived as threatening by and to others. Criminals and social deviants are stigmatized because they create a sense of anxiety by threatening society's values and safety. Similarly, encounters with sick and disabled individuals also cause anxiety and apprehension, but in a different way. The encounter destroys the dream that life is fair. Sick people remind us of our mortality and vulnerability; consequently, physically healthy individuals may make negative value judgments about those who are ill or disabled (Kurzban & Leary, 2001). For example, some sighted individuals may regard those who are blind as being dependent or unwilling to take care of themselves, an assumption that is not based on what the blind person is willing or able to do. Individuals with AIDS are often subjected to moral judgment. Those with psychiatric illness have been stigmatized since medieval times (Keltner, Schwecke, & Bostrom, 2003). As a result, these individuals deal with more than their symptomatology; on a daily basis they contend with those who perceive them as less worthy or valuable, because they possess a stigma.

Some individuals are stigmatized because the behavior or difference is considered to be self-inflicted and, therefore, less worthy of help. Alcoholism, drug-related problems, and mental illness are frequently included in this category (Crisp et al., 2000; Ritson, 1999). In fact, alcoholism as a disease is highly stigmatized as compared to other mental illnesses (Schomerus et al., 2010). HIV/AIDS and hepatitis B are examples of infectious diseases in which the mode of infection is considered to be self-inflicted as a result of socially unacceptable behavior; therefore, affected

individuals are stigmatized (Halevy, 2000; Heckman et al., 2004).

In the past, the words “shame” and “guilt” were used to describe a concept similar to stigma—a perceived difference between a behavior or an attribute and an ideal standard. From this perspective, guilt is defined as self-criticism, and shame results from the disapproval of others. Guilt is similar to seeing oneself as discreditable. Shame is a painful feeling caused by the scorn or contempt of others. For example, a person with alcoholism may feel guilty about drinking and also feel ashamed that others perceive his or her behavior as less than desirable.

Whenever a stigma is present, the devaluing characteristic is so powerful that it overshadows other traits and becomes the focus of one’s personal evaluation (Kurzban & Leary, 2001). This trait, or differentness, is sufficiently powerful to break the claim of all other attributes (Goffman, 1963). As an example, the fact that a nurse has unstable type I diabetes may cancel her/his remaining identity as a competent health professional. The stigma attached to a professor’s stutter may overshadow academic competence.

The extent of stigma resulting from any particular condition cannot be predicted. Individuals with a specific disease do not universally feel the same degree of stigma. On the other hand, very different disabilities may possess the same stigma. In writing about individuals with mental illness, Link and colleagues (1997) described variations in symptomology among them; however, individuals without mental illness did not take those variations into account. All individuals who were disabled were seen as sharing the same stigma—mental illness—regardless of their capabilities or severity of their illness. That is, people responded to

the mental illness stereotype rather than to the person’s actual physical and mental capabilities.

Similarly, Herek, Capitano, and Widaman (2003) reported on the stigmatizing effects of the label of HIV/AIDS. They found that those individuals who reported a perceived reduction in the level of stigma attached to HIV/AIDS overall still generally expressed negative feelings toward people with AIDS and favored a name-based reporting system such as that used by the public health department for other communicable diseases.

Types of Stigma

Stigma is a universal phenomenon and every society stigmatizes. Goffman (1963) distinguished among three types of stigma. The first is the stigma of physical deformity. The actual stigma is the deficit between the expected norm of perfect physical condition and the actual physical condition. For example, many chronic conditions create changes in physical appearance or function. These changes frequently create a difference in self- or other-perception (see Chapter 6).

Stigma can arise from a normal physiological process—aging. The normal aging process creates a body far different from the television commercial “norm” of youth, physical beauty, and leanness. Younger people tend to differentiate themselves from older people based on the differences in appearances, physique, and mentality. Butler (1975) first termed “the process of systemically stereotyping and discriminating against people because they are old” as ageism (p. 894). Detrimental consequences may follow after labeling a person as elderly, senior citizen, or aged. For example, a person who is hard of hearing may refuse to use a hearing aid to avoid

being labeled as “getting old”. In fact, hearing loss was considered a perceived stigma in aging and the use of hearing aids was associated with being disabled in one longitudinal qualitative study (Wallhagen, 2010). In another study, adults ($n = 103$) 60 to 70 years old were found to be more sensitive to stereotyping threats affecting memory performance (Hess, Hinson, & Hodges, 2009). In other words, if the older adult is conscious of how his or her behavior may reflect negatively on the older adult population, he or she may have increased anxiety and reduced memory capacity. Although physical decline, loneliness, and depression in the older adult have been well documented in the literature, interventions must be implemented to enhance “positive aging” (Stephens & Flick, 2010). Health promotion and positive aging attitudes can only be accomplished when the stigma of ageism is abolished.

The second type of stigma is that of character blemishes. This type may occur in individuals with HIV/AIDS, alcoholism, mental illness, or sexually transmitted diseases. For example, individuals infected with HIV face considerable stigma because many believe that the infected person could have controlled the behaviors that resulted in the infection (Halevy, 2000; Heckman et al., 2004; Herek et al., 2003; Weston, 2003). Likewise, individuals with eating disorders such as anorexia nervosa fear being stigmatized (Stewart, Keel, & Schiavo, 2006). The fear of stigma can be a major barrier to seeking treatment.

The third type of stigma is tribal in origin and is known more commonly as prejudice. This type of stigma originates when one group perceives features of race, religion, or nationality of another group as deficient compared with their own socially constructed norm. Most

healthcare professionals agree that prejudice has no place in the healthcare delivery system. Although some professionals display both subtle and overt intolerance, others strive to treat persons of every age, race, and nationality with sensitivity. However, prejudice against individuals with chronic illnesses exists as surely as racial or religious prejudice.

The three types of stigma may overlap and reinforce each other (Kurzban & Leary, 2001). Individuals who are already socially isolated because of race, age, or poverty will be additionally hurt by the isolation resulting from another stigma. Heukelbach and Feldmeier (2006) stated that scabies infestations are associated with poverty in undeveloped countries, which contributes to the stigmatization of both diagnosis and treatment. Those who are financially disadvantaged or culturally distinct (that is, stigmatized by the majority of society) will suffer more stigma should they become disabled. Poor women with HIV feared the stigma associated with HIV/AIDS more than dying of the disease (Abel, 2007).

Psychologists and sociologists have built on Goffman’s theory to address the concepts of felt stigma and enacted stigma (Jacoby, 1994; Scambler, 2004). Felt stigma is the internalized perception of being devalued or “not as good as” by an individual. It may be related to fears of being treated differently or of being labeled by others, even though the stigmatizing attribute is not known or outwardly apparent. The other component of felt stigma is shame (Scambler, 2004). Individuals view themselves as discreditable. The quote at the beginning of this chapter is an example of a client experiencing felt stigma.

Enacted stigma, on the other hand, refers to behaviors and perceptions by others toward the individual who is perceived as different. Enacted

stigma is the situational response of others to a visible, overt stigmatizing attribute of another (Jacoby, 1994; Scambler, 2004). Hesitating or failing to shake hands with a person who has vitiligo, a dermatologic condition characterized by hypopigmentation of the skin, is an example of enacted stigma.

Felt and enacted stigma may overlap. “Smoke-free” regulations are now in effect across the United States and abroad. Whereas these laws have been enacted to protect the public from the carcinogens and toxins present in secondhand smoke, the smoking behavior may be viewed as an unfavorable attribute. By association, the individual who smokes may be seen as “less than” or as less favorable. Thus, the individuals who smoke may experience both felt stigma and enacted stigma. Indeed, some smokers and recent ex-smokers in Scotland described themselves as “lepers” (Ritchie, Amos, & Martin, 2010). The temporary segregation occurring as a result of “smoking sections” led them to stigmatize themselves as well as their behaviors and that of other smokers.

Stigma is prevalent in our society and, once it occurs it endures (Link et al., 1997). If the cause of stigma is removed, the effects are not easily overcome. An individual’s social identity has already been influenced by the stigmatizing attribute. A person with a history of alcoholism or mental illness continues to carry a stigma in the same way that a former prison inmate does.

Chronic Disease as Stigma

Individuals with chronic illness present deviations from what many people expect in daily social interchanges. In general, most people do not expect to meet someone with an electronic voice-box following treatment for laryngeal

cancer. Both the cancer and the assistive device may not be readily visible, but once the person begins to speak, the individual is at risk of being labeled as “different” by others.

American values contribute to the perception of chronic illness as a stigmatizing condition. That is, the dominant culture emphasizes qualities of youth, attractiveness, and personal accomplishment. The work ethic and heritage of the Western frontier provide heroes who are strong, conventionally productive, and physically healthy. Television and magazines demonstrate, on a daily basis, that physical perfection is the standard against which all are measured, yet these societal values collide with the reality of chronic disease. A discrepancy exists between the realities of a chronic condition, such as arthritis or HIV/AIDS, and the social expectation of physical perfection.

A disease characteristic or one having an unknown etiology may contribute to the stigma of many chronic illnesses. In fact, any disease having an unclear cause or ineffectual treatment is suspect, including Alzheimer’s disease (Jolley & Benbow, 2000) and anxiety disorders (Davies, 2000). Clients with Alzheimer’s disease also may be stigmatized because of perceptions relating to their level of decision-making competence (Werner, 2006). Diseases that are somewhat mysterious and at the same time feared, such as leprosy, are often felt to be morally contagious.

Stigma can be associated with inequitable treatment, although the relative severity of such inequitable treatment often varies with the degree of severity of the stigmatized condition. For example, public policy about HIV/AIDS has acted both to increase accessibility to treatment and potentially to limit the civil rights of the stigmatized individuals (Herek et al., 2003). In addition, the shame, guilt, and social isolation of some stigmatized individuals may lead to

inequitable treatment for their families. Because of the secrecy associated with being HIV-positive, affected clients and family members may not be able to access needed mental health, substance abuse rehabilitation, or infectious disease therapies (Salisbury, 2000).

The stigma associated with HIV/AIDS or the associated high-risk behaviors may impact public health screening efforts (Glasman, Weinhardt, DiFranceisco & Hackl, 2010). Men of Mexican descent were less likely to participate in free HIV-screening events. Findings suggested that participation in HIV testing could stigmatize these men due to the association of HIV infection with high-risk behaviors (men having sex with men, illicit drug use). By avoiding testing, these men were avoiding the possibility of enacted stigma. A study of Irish women of childbearing age found the same reasoning behind avoiding screening for chlamydia (Balfe et al., 2010). Undergoing screening for the disease was associated with risky behaviors and promiscuity, which would result in felt stigma and possibly enacted stigma.

This chapter has defined stigma and presented a framework for understanding stigma as a social construct. All types of stigma share a common tie: In every case, an individual who might have interacted easily in a particular social situation may now be prevented from doing so by the discredited trait. The trait may become the focus of attention and potentially turn others away.

IMPACT OF STIGMA

Stigma has an impact on both the affected individual and those persons who do not share the particular trait. Responses to stigma vary and will be discussed from the perspective of the person living with stigma, the layperson, and the healthcare professional.

The Individual Living with Stigma

Stigmatized individuals respond to the reactions of others in a variety of ways. They are often unsure about the attitudes of others and, therefore, may feel a constant need to make a good impression. Individuals living with stigma each and every day may choose to accept society's or others' view of them, or choose to reject others' discrediting viewpoints. Culture may limit the coping choices that are available, particularly in relation to disclosing a mental illness. In a study of West Indian women coping with depression, Schreiber, Stern, and Wilson (2000) found that "being strong" was the culturally sanctioned behavior for depression, rather than disclosure.

Passing

Passing oneself off as "normal" is one strategy used by individuals living with a stigmatizing condition. Pretending to have no disability or a less stigmatic identity (Dudley, 1983; Goffman, 1963; Joachim & Acorn, 2000) may be an option if the stigmatizing attribute is not readily visible. Passing is a viable option for those with felt stigma associated with conditions such as type II diabetes or a positive AIDS antibody test but no symptoms. The process of passing may include the concealment of any signs of the stigma. Some individuals refuse to use adaptive devices, such as hearing aids, because this tells others of their disability. Another example is the abused client who provides reasonable explanations for bruises, swelling, and injuries. The practice of "passing" may significantly impair the health-seeking behavior of the abused individual, particularly where sociocultural barriers to disclosure exist (Bauer, Rodriguez, Quiroga, & Flores-Ortiz, 2000).

CASE STUDY



Case Study #1

Richard Wilson is a 43-year-old, married, high school science teacher. He is 100 pounds overweight and smokes cigarettes (1 pack per day for the past 20 years). He is thankful that he is in reasonably good health, although he does state that, “my doctor started making me take a blood pressure pill every day when I saw her 2 months ago.” Mr. Wilson lives in a state that has recently enacted smoke-free legislation. He rarely travels because he is concerned that he “will not fit in those tiny airplane seats.”

Discussion Questions

1. What type of stigma is Mr. Wilson at risk for? How would you assess this client’s self-perception of stigma?
2. What strategies can the healthcare provider offer this client to reduce the effects of stigma?
3. At Mr. Wilson’s next blood pressure check appointment, how can the nurse evaluate whether the client has made progress in reducing felt and/or enacted stigma?
4. What strategies can the healthcare professional use to help break through the barriers of enacted stigma by members of the healthcare team toward individuals with negatively perceived lifestyle behaviors?
5. One goal stated in the *Healthy People 2020* document is to promote healthy nutrition and weight. How can the healthcare professional assess nutritional status and make recommendations for behavioral change without stigmatizing the individual?

Case Study #2

Dr. Min Pak is a 78-year-old retired nursing professor from Korea. While visiting her son in the United States, she developed nausea, vomiting, diarrhea, and abdominal pain. She went to a nearby urgent care center. The nurse at the urgent care center just finished checking her vital signs.

Dr. Pak: What are my blood pressure and temperature?

Nurse: Blood pressure is a little low and you have a low-grade temperature.

Dr. Pak: Could you please tell me the numbers?

Nurse: Blood pressure is in the 90s and you have a slight fever. Trust me, you don’t need to know the exact numbers. By the way, when was the last time you had something to eat or drink, sweetie?

Dr. Pak: [thinking]

Nurse: When did you last have something to eat or drink? [*speaking louder and gesturing eating and drinking with mouth and hand*]

Dr. Pak: I heard you. That was 3 hours ago.

CASE STUDY (Continued)



Nurse: You marked on the health form that you have chronic pancreatitis. How often and how much do you drink? And, of what kind?

Discussion Questions

1. What type of stigma is Dr. Pak experiencing?
2. Describe the nurse's attitudes and perceptions of stigma.
3. What interventions to reduce stigma would you suggest the client and the healthcare provider implement?
4. What are the implications for professional nursing practice?

Covering

Because of the potential threat and anxiety-provoking nature of disclosing a stigmatizing difference, most people deemphasize their difference. This response, called covering, is an attempt to make the difference seem smaller or less significant than it really is (Goffman, 1963). Covering involves understanding the difference between visibility and obtrusiveness; that is, the condition is openly acknowledged, but its consequences are minimized. Persons with special dietary requirements may deny the importance of maintaining the restriction in a social situation, even though they follow it. The goal is to divert attention from the defect, create a more comfortable situation for all, and minimize the risk of experiencing enacted stigma.

Humor, used in a skillful and lighthearted manner by the stigmatized individual, may decrease the anxiety of others and avoid an awkward encounter. This form of covering neutralizes the anxiety-producing subject; therefore, it is no longer taboo and can more easily be managed.

Disregard

A person's first response to enacted stigma may be disregard. In other words, they may choose not

to reflect on or discuss the painful incidents. Well adjusted individuals who are comfortable with their identity, have dealt with stigma for a long time, and choose not to respond to the reaction of others, may disregard it (Dudley, 1983).

Other examples are wheelchair athletes. These athletes disregard perceptions that their disabilities prohibit them from participating in strenuous, athletic endeavors. Any person who has observed these well conditioned athletes racing their wheelchairs up hills in competitive meets may find it difficult to consider them discredited.

Going public with a serious medical diagnosis is another example of disregard by acting in the face of negative consequences. One positive aspect of going public is the potential for assertive political action and social change. Celebrities such as Muhammed Ali, Earvin (Magic) Johnson, Michael J. Fox, and the late Christopher and Dana Reeve, among others, have captured public attention and acted positively to reduce enacted stigma by disclosing their personal struggles with a variety of conditions.

Resistance and Rejection

Similar to disregard, resistance and rejection are additional strategies used in response to stigma

(Dudley, 1983). Individuals may speak out and challenge rules and protocol if their needs are not met. More recently, Franks, Henwood, and Bowden (2007) noted that resisting and rejecting were strategies used by maternal mental health clients. These disadvantaged mothers outright rejected or actively resisted the judgments of professionals who held negative opinions. Broader societal misconceptions, such as the belief all teen mothers are on welfare, also were rejected. The use of resistance or rejection can be used to preserve or bolster a more positive self-identity and effect larger societal changes.

Isolation

Human beings have a proclivity for separating themselves into small subgroups because staying with one's own group is easier, requires less effort, and, for some individuals, is more congenial. However, this separation into groups tends to emphasize differences rather than similarities (Link et al., 1989; see Chapter 5).

Closed interaction from within may enhance one's feelings of normality because the individual is surrounded by others who are similar (Camp et al., 2002). The process of isolation can occur any time outsiders are seen as threatening or are reminders that the world is different from the in-group.

Staying with like others may be a source of support, but some individuals with a disability or chronic illness may feel more comfortable when they are surrounded by nondisabled individuals. A young woman, disabled since birth, feels better around nondisabled people because she has always considered herself normal. Her attitude reminds us to use caution when making assumptions about the perceptions of others.

Information Management

In addition to the stigmatized individual, family members often acquire a secondary stigma as a result of association (Goffman, 1963) and must deal with their own responses to situations of enacted stigma. Mothers who are HIV-positive expend significant effort to protect their children from the negative effects of disclosure of their HIV status (Sandelowski & Barroso, 2003). Likewise, family members who care for persons with HIV/AIDS share the stigma and are discredited, resulting in rejection, loss of friends, and harassment (Gewirtz & Gossart-Walker, 2000; Salisbury, 2000).

Information management is used by both the individual and loved ones in dealing with felt and enacted stigma. The world may be divided into a large group of people to whom they tell nothing and a small group of insiders who are aware of the stigmatizing condition. Healthcare professionals may use information management in an attempt to lessen the likelihood of stigma for a client. For example, listing a diagnosis of Hansen's disease or mycobacterial neurodermatitis gives the client the option of revealing the alternate name of leprosy, with its accompanying historical stigma.

The Layperson: Responses to and Effects of Stigma

Responses of an individual to a stigmatized person vary with the particular stigma and the individual's past conditioning. Because society specifies the characteristics that are stigmatized, it also teaches its members how to react to that stigma. Differences between groups based on nationality and culture have been found in attitudes toward those with disabilities (Brandon et al., 2000; Cinnirella &

Loewenthal, 1999). Just as children learn to interact with others who are culturally different by watching and listening to those around them, they also learn how to treat individuals with chronic illness or disabilities by incorporating societal judgments. Sadly, these reactions are often negative.

With the advances in telecommunication and electronic communication, the general public is more aware of chronic physical and mental illnesses. Yet an online survey by the American Psychiatric Association (2010) on the perception of mental illness found that the stigma still persisted. Adults ($n = 2,285$) who responded to the survey revealed an increased acceptance to mental disorders, especially when they had a personal experience of the disease with family and friends. Other responders kept a more open mind after obtaining accurate information on mental illnesses from the mass media, celebrity figures, and Internet sources.

Devaluing

People may believe that the person with the stigma is less valuable, less human, or less desired. Unfortunately, many of us practice more than one kind of discrimination and, by so doing, effectively reduce the life chances of the stigmatized individual (Goffman, 1963). Devaluing results in enacted stigma as demonstrated by those who categorize individuals as inferior or even dangerous. Use of words such as “cripple” or “moron” also represent a devaluing of individuals.

Stereotyping

Categories simplify our lives. Instead of having to decide what to do in every situation, we can respond to categories of situations. Stereotypes

are a negative type of category. They are a social reaction to ambiguous situations and allow us to react to group expectations rather than to individuals. When individuals meet those with physical impairments, expectations are not clear (Katz, 1981). People often are at a loss as to how to react, so placing the individual with chronic illness in a stereotyped category reduces the ambiguity toward him or her and makes the situation more comfortable for those doing the stereotyping. Much less effort is required to sustain a bias than is required to reconsider or alter it.

Using stereotypes to understand individuals decreases our attention to other positive characteristics (Hynd, 1958). Categorizing tends to make one see the world as a dichotomy. For example, people are categorized as either mentally delayed or not, even though mental capabilities exist on a continuum, with all of us falling somewhere along the line.

Responses such as scapegoating and ostracizing people with HIV/AIDS have increased the impact of this disease and delayed treatment (Distabile, Dubler, Solomon, & Klein, 1999; Rehm & Franck, 2000; Salisbury, 2000). These responses also impede appropriate health education aimed at prevention.

Labeling

The label attached to an individual's condition is crucial and influences the way we think about that individual. The diagnosis of HIV/AIDS is a powerful label, possibly resulting in the loss of relationships and jobs. People with learning disabilities may not mind being called slow learners, but may be startled by being called mentally retarded (Dudley, 1983). Their response indicates that they see this latter term as a negative label.

Professional Responses: Attitudes and Perceptions of Stigma

In the United States, most healthcare professionals share the American dream of achievement, attractiveness, and a cohesive, healthy family. These values influence our perceptions of individuals who are disabled, chronically ill, or otherwise considered “less than normal.” Although the factors that contribute to these individual differences vary, the consequences of stigma associated with chronic illnesses are similar in different health conditions and cultures (Van Brakel, 2006).

Attitudes

It is not surprising that society’s values and definitions of stigma affect the attitudes of healthcare professionals. Attitudes can be changed by interactions with clients and acquaintances with chronic illness (Sandelowski & Barroso, 2003). Students’ confidence in clients’ ability to cope with a disease increased with professional experience. In a similar manner, knowing someone with a chronic disease increased positive attitudes. When healthcare professionals (general practitioners, nurses, and counselors) were asked about their perceptions of depression among older adults, they agreed that the older adults displayed embarrassment and shame when disclosing feelings of depression. Older adults were perceived as reluctant to seek mental health services because depression was identified as a stigma. Whether these perceptions of the healthcare professionals are consistent with those of the older adults will require further examination (Murray et al., 2006).

Perceptions

Healthcare professionals’ perceptions of stigma affect care outcomes. Liggins and Hatcher

(2005) studied the stigma of mental illness in the hospital setting. Labeling a client as mentally ill had a negative impact on both the client and the healthcare professional. Clients believed that they were ignored or treated differently because they had mental illness. They feared how the healthcare professional would respond to them. The healthcare professional showed disbelief toward physical ailments because the client had “mental disease.” Healthcare providers also assumed that mental illness was associated with an unpredictable behavior that might affect the healthcare professional–client relationship (Liggins & Hatcher, 2005). Clearly, interventions to reduce perceptions of stigma and episodes of enacted stigma in the hospital setting are needed.

The attitude of the healthcare provider is vital in reducing the stigma associated with chronic illness. Healthcare professionals who are nonjudgmental, empathic, and knowledgeable were observed to reduce the perception of stigma in a specialized HIV/AIDS unit. Stigma was minimized when nurses and other interdisciplinary team members identified themselves with the behaviors of the clients, held a positive view of the disease, and reached consensus in the delivery of appropriate care (Hodgson, 2006).

Another study of medical students’ perspectives of illness disclosed a surprising aspect of stigma. Medical students revealed a high level of concern over the perception of social stigma attached to their own personal health problems and the resulting professional jeopardy they might encounter upon disclosure (Roberts, Warner, & Trumppower, 2000).

Healthcare professionals potentially display all the reactions and responses toward discredited individuals that laypersons do.

Therefore, caregivers need a thorough understanding of these responses if we are to overcome the effects of stigmatizing behavior or to eliminate it outright. Understanding the concept of stigma increases one's ability to plan interventions for clients with chronic illnesses (Joachim & Acorn, 2000).

INTERVENTIONS: COPING WITH STIGMA OR REDUCING STIGMA —

A chronic illness or disability imposes various constraints on an individual's life. The stigma of a specific disorder adds additional burdens, often far greater than those caused by the disorder itself (Joachim & Acorn, 2000). Individuals with chronic conditions usually receive medical treatment, but few interventions may be directed at reducing the effects of the associated stigma.

Helping others to manage the effects of stigma is not simple and should be approached with care. At best, change will be slow and uneven. However, consistent and knowledgeable interventions aimed specifically at reducing the impact of stigma are as crucial as those that reduce blood pressure or chronic pain. The following section discusses appropriate strategies healthcare providers can employ in their practice to address the issue of stigma.

National Healthcare Reform

Alleviating stigma is more effective in a politically supportive environment. As part of the healthcare reform under the Obama administration, the U.S. Congress passed the Health Reform Act (Healthcare.gov, 2010). This act combined both the Patient Protection and Affordable Care Act and the Healthcare Education and Reconciliation Act of 2010. The

Health Reform Act proposed an increase in coverage in the treatment of mental illness and substance abuse. Clients with a pre-existing health condition such as cancer, HIV/AIDS, substance abuse, or mental illness will not be denied treatment. Funding will be provided to develop programs in Medicaid and in the community to improve the coordination and quality of behavioral healthcare services. In addition, grants will be offered for projects and research to increase the public awareness of mental health and substance abuse prevention and management. It is hoped that by increasing awareness of the nature of chronic illnesses and addictions among the general public, and with increased accessibility to health care for all, the issue of stigma attached to the aforementioned problems will be decreased.

Healthcare Professional and Client Interactions

The healthcare professional who is aware of his or her own biases, beliefs, and behaviors has already begun to mitigate the effects of stigma for the client and family members. Being aware of the societal context and implications that a diagnosis of chronic illness carries with it enables the healthcare professional to work with the client to develop strategies to prevent, reduce, or cope with potentially stigmatizing conditions.

Professional Attitudes: Cure versus Care

Traditionally, the goal of health care has been to cure the client. Because chronic illness is now more prevalent than infectious disease or acute illness, this criterion of success may be inappropriate. Cure is neither essential nor necessary in order that the client benefit. Instead, caring,

demonstrated by valuing and assisting, should be the criterion. With the increasing number of people with chronic illnesses, professionals must learn to accept those characteristics accompanying chronic illness: an indeterminate course of disease, relapses, and multiple treatment modalities. Cost containment is a central focus in healthcare delivery. Providers must not lose sight, however, of health policy considerations that include ideas of personhood and equitable health care sensitive to the reality of stigmatizing chronic illness (Gewirtz & Gossart-Walker, 2000; Roskes, Feldman, Arrington, & Leisher, 1999; Salisbury, 2000).

The Mutual Participation Model

The manner in which health care is delivered may increase or decrease the effects of stigma. Encouraging a client's participation in healthcare decision making is an outward demonstration of respect and regard for that person. Establishing the client as a partner in setting goals demonstrates one's acceptance and valuing of the individual. On the other hand, when healthcare professionals make decisions regarding treatment or goals without consulting a client, they reinforce the person's feeling of being discredited or discreditable. Therefore, any mode of care delivery that increases client participation enhances that person's perception of self-worth and reduces the effects of stigma. The mutual participation model is the model of choice in managing chronic diseases because it enhances the client's feelings of self-worth. The client is responsible for long-term disease management, and the healthcare professional is responsible for helping the client help him- or herself.

Mutual participation divides power evenly between professional and client and leads to a

relationship that can be mutually satisfying. In other words, the client should be as satisfied with the recommendations and decisions as the provider is. In addition, each party depends on the other for information culminating in a satisfactory solution. The client needs the provider's experience and expertise; the provider needs not only the client's history and symptoms but his or her priorities, expectations, and goals. Sometimes a choice between treatments with relatively equal mortality rates is necessary—for example, surgery or radiation for cancer treatment. The professional can offer expert knowledge regarding long-term effects of radiation and changes in body image due to surgery. The client must decide the relative value of side effects of the alternative proposed treatments. Because the "right" decision depends on the individual, input from both client and healthcare provider is necessary to produce a course of action that is mutually acceptable.

When healthcare professionals become more comfortable with allowing clients a greater range of participation and decision making, the relationship decreases some of the stigmatizing effects of the disability. Healthcare professionals must create an atmosphere in which individuals with chronic conditions not only are expected to cooperate, but are encouraged to express their concerns, observations, expectations, and limitations. Together, they explore alternative strategies and decide on one that is agreeable to both. When a client's priorities and goals are valued and incorporated into the regimen, an increased sense of acceptance emerges. Therefore, the respect and regard for clients demonstrated by this model provide effective tools to counteract some stigmatizing effects of illness.

Healthcare professionals who establish a therapeutic relationship with their client are ideally situated to assess their client's perceptions of felt or enacted stigma. Asking open-ended questions to ascertain how the client perceives himself or herself, the meaning of the disease to the client, and types of interactions with others may elicit valuable information. Family members and significant others may be included in the assessment as well.

It is particularly important to distinguish between nonparticipation and nonacceptance when caring for stigmatized individuals. Nonparticipation is an abstinence from social activities that is based on limitations caused by a disability or illness. Nonacceptance, on the other hand, is a negative attitude—a resistance or reluctance on the part of the nondisabled person to admit the disabled person to various kinds and degrees of social relationships (Ladieu-Leviton, Adler, & Dembo, 1977). A person with a disability who chooses not to join a camping trip is a nonparticipant; the physical disability serves as the basis for that person's decision not to participate. Deciding not to invite that person to join the group, whether or not participation is possible, is nonacceptance; it preempts the person's choice and is a form of enacted stigma.

Commonly, individuals without a disability cannot accurately estimate the limits of potential participation for those with a disease or disability—a key point for healthcare professionals to remember. Typically, the physical limitations imposed by a disability are overestimated by others. If nondisabled individuals incorrectly assume that a disabled individual is not able to participate, that is a form of nonacceptance. Such nonacceptance is created by the difference between the degree of participation that is actually

possible and the degree assumed possible by those who are not disabled. If the difference can be resolved, nonacceptance ceases to be a problem.

The remedy for this dilemma is simple. Nondisabled individuals can simply indicate that they want the disabled individual to participate, leaving to him or her the decision of whether to become involved. Perhaps the individual with the disability would like to participate, but in a different way. For example, the young adult who has juvenile arthritis may not regret being unable to actually fish if he or she can go along on the trip and spend time socializing with friends. Healthcare professionals can encourage their clients to look for these opportunities to participate as they are able.

Family members or significant others who are involved in the client's care must not be forgotten. An ethnographic study of immediate family members of burn survivors explored the perceptions of stigma (Rossi, Vila Vda, Zago, & Ferreria, 2005). The stigma associated with the burn and the accompanying feelings of loss of control affected both the client and the family. The family had fears of facing the reactions from society, which encompassed feelings of sadness, anger, denial, resignation, and/or anxiety. Some family members expressed feelings of shame when living with someone whose role and appearance changed due to the burn injuries. Thus, it is imperative that the perceptions of both the stigmatized person and the family are assessed.

Client-Centered Interventions

Strategies to Increase Self-Worth

Societal norms and values are a major determinant of an individual's sense of self-esteem and self-worth. The person who does not possess the

expected attribute is quite aware of this discredit as an equal and desired individual in society. In addition, individuals with chronic conditions may find their own deformities or failings decrease their self-respect. That is, not only do stigmatized individuals have to deal with the responses of others (enacted stigma), but some experience strong negative feelings about their own self-worth (felt stigma). These internalized perceptions may be more difficult to deal with than the illness or disability itself. Examples of negative feelings were described by 60 study participants with epilepsy. More than half of the participants experienced feelings of shame, fear, worry, and low self-esteem, and one-fourth had the perception of stigma (de Souza & Salgado, 2006).

In another study, obese individuals and their family members noted both stigmatization and discrimination on the basis of weight. They reported being constantly reminded by family members, peers, healthcare providers, and strangers that they were inferior as compared to those who were not obese (Rogge, Greenwald, & Golden, 2004).

In an attempt to change self-perception of stigma, Abel (2007) utilized an intervention of emotional writing disclosure for women with HIV. Women who participated in the intervention had more positive scores on the Stigma Scale tool at the end of the 12-week pilot study than women in the control group. The stigma scale is a 28 item self-report questionnaire developed to measure the stigma felt by clients with psychiatric illness (King, Dinos, Shaw, Watson, Stevens, Passett et al., 2007). This journaling strategy may be one way the healthcare provider can help individuals change their internal perception of stigma.

With these internalized negative perceptions, some people with chronic illness choose to conceal the disease. When 14 people with a diagnosis of multiple sclerosis and their families

were interviewed, it was found that the disease was purposefully concealed or selectively disclosed to shield from social judgment or to enhance social belonging at work (Grytten & Maseide, 2005). In describing studies of clients with cerebral palsy, cancer, facial deformity, arthritis, and multiple sclerosis, Shontz (1977) noted that the personal meaning of the disability to each client was uniformly regarded as crucial. For example, individuals who feel valuable because they are healthy and physically fit usually experience feelings of worthlessness if they contract a chronic condition. But people with diabetes will never be without a regimen and the necessary paraphernalia; visually impaired individuals will never see normally again. Therefore, the individuals' reactions and ability to accommodate these discrepancies determine their attitudes of worth and value.

In contrast, some individuals with chronic conditions can accept deviations from expected norms and feel relatively untouched. They have reordered life's priorities; no longer is the absence of disease or disability their major criterion for self-worth. Rather, an alternative ideology evolves to counter the "standard" ideologies. A strong sense of identity protects them, and they are able to feel acceptable in the face of the stigma (Goffman, 1963).

This identity belief system, also called cognitive belief patterns, refers to a person's perspective. It includes one's perceptions, mental attitudes, beliefs, and interpretations of experiences (Link et al., 1997). Individuals who are stigmatized by the major society may believe and perceive that their groups are actually superior or at least preferable. These belief patterns offer protection from the stigmatized reactions of others. Yet, being in a specific cultural or ethnic group does not always provide protection

against stigma in certain diseases. In fact, the stigma of having a mental illness is even more prominent among some ethnic groups. A literature review by Gary (2005) found that African Americans, Asian Americans, Hispanic Americans, and Indian Americans all perceived stigma related to mental illness in addition to the prejudice and discrimination already experienced due to the affiliation with their particular ethnic group.

Cognitive belief patterns help individuals with chronic illnesses achieve identity acceptance and protection in the face of stigmatizing conditions. For example, after extensive cancer surgery, clients may consciously tell themselves that they are full human beings because the missing part was diseased or useless. The body, although disfigured, is now healthy and totally acceptable. Similarly, wheelchair athletes take pride in their superb physical condition and competitiveness. That is, one's perception of self-worth influences one's reactions to disease or disability. An individual's question, "Am I worthwhile?" is answered by determining his or her own values and perspective. Therefore, clients' definitions of themselves are crucial factors in self-satisfaction.

Support Groups

Goffman (1963) used the term *the own* for those who share a stigma. Those who share the same stigma can offer the "tricks of the trade," acceptance, and moral support to a person living with stigma. Self-help or support groups are examples of persons who are the own. Alcoholics Anonymous (AA), for instance, provides a community of the own as well as a way of life for its members. Members speak publicly, demonstrating that people with alcoholism are treatable, not terrible, people.

Groups composed of people with similar conditions can be formal or informal and are enormously helpful. First, peer groups can be used to explore all of the potential response options discussed previously, such as resisting and passing. Second, problem-solving sessions in these groups explore possible solutions to common situations (Dudley, 1983). Finally, others who share the stigma provide a source of acceptance and support for both the individuals with the chronic condition and their families. Maternal mental health clients developed and implemented an ongoing support group in consultation with a healthcare professional (Franks et al., 2007). These women were able to promote and sustain their group for a 12-month period.

O'Sullivan (2006) reported on a unique twist to the self-help group. A Barcelona, Spain radio program was planned and implemented by persons with mental illness. The program sought to inform, educate, and break down the stigma and stereotypes associated with mental illness. Benefits to the participants included an increase in self-esteem and more positive self-perception.

A word of caution is needed. Sometimes stigmatized individuals feel more comfortable with nonstigmatized individuals than with like others as a result of a closer identity with the former. For example, not all women with cancer respond positively to the American Cancer Society's Reach to Recovery support groups; some may feel more discomfort than support.

Reputable online support groups present another option for people with the technologic equipment and skills to access these resources. The ability to control the encounter with like others in a safe haven may be appealing to many clients. The advent of social media sites such as Facebook may alter the way individuals access and develop support networks as well. Social

sites may offer another means of establishing both social and supportive relationships with the amount of disclosure controlled by the person. One must be aware of the potential for misuse, misrepresentation, and violations of privacy that could occur. Research in this area is sorely needed. Ultimately, the “best” solution varies from individual to individual.

Other Considerations

Other points for the healthcare professional to consider are issues of “inclusion” and “exclusion,” and how they impact stigma. Technology and assistive devices are significant factors because they underline the fact that “quality of life” is not a static entity. Until relatively recently, electric wheelchairs were not readily available. Now such wheelchairs exist, in pediatric to bariatric sizes, as well as electric scooters that allow mobility for clients with a variety of conditions. Formerly, a person with paralyzed arms could only type slowly with a stick fastened to a headband; now there are increasingly accurate voice-activated home computers that type as the person speaks. In the same vein, a person whose speech is unintelligible to most others can press symbols on a display board that produces full sentences spoken in a nonrobotic, smooth human voice. The savvy healthcare professional will attend to technologic advances and assist clients in obtaining necessary aids to promote full functioning of the individual.

To that end, the opportunity to hire personal assistants is also important. Having such assistance allows individuals with severe disabilities to have a far richer life than those without such help. Many disability advocates are pressing for public money that is currently spent on nursing homes and other institutions to be redirected to enable individuals who are

disabled or chronically ill to live in their own homes (see Chapter 23). Maintaining function and independence may lessen the impact of both felt and enacted stigma.

Developing Supportive Others

Supportive others are persons (professional and nonprofessional) who do not carry the stigmatizing trait but are knowledgeable and offer sensitive understanding to individuals who do carry it. These people are called *the wise* by Goffman (1963) and are accorded acceptance within the group of stigmatized individuals. Desired behaviors are simply the ones friends or acquaintances would use. The stigmatized person must be seen and treated as a full human being—viewed as more than body changes or orthopedic equipment, seen as a person who is more than a stigmatized condition.

The AIDS epidemic has added to the impetus for the development of groups of supportive others. In many cities, the model of care for those with HIV/AIDS depends on volunteer, community-based groups that supply food, transportation, in-home care, acceptance, and support. This community network is an adjunct to hospital care and provides a vivid example of wise others who are essential to the care of these clients.

Implications for Professional Practice

One way an individual can become wise is by asking straightforward, sensitive questions, such as inquiring about the disabled person’s condition. Many individuals with disabilities would welcome the opportunity to disclose as much or as little as they wish, because that would mean that the disability was no longer taboo. For example, the disabled person may prefer that

others ask about a cane or a walker rather than ignore it. This opportunity allows the disabled individual to reply with whatever explanation he or she wishes. Therefore, the disability is acknowledged, not ignored. It goes without saying that these questions should be asked after a beginning relationship is established, as opposed to being asked out of idle curiosity.

The process of becoming wise is not simple; it may mean offering oneself and waiting for validation of acceptance. Healthcare professionals who encounter individuals with chronic illness cannot prove themselves as wise immediately. Validation requires consistent behavior by the professional that is sensitive, knowledgeable, and accepting. Being wise is not a new role for nurses or other caring healthcare professionals. Nurses have traditionally worked in medically underserved areas with discredited persons and are accustomed to treating clients as individuals, not as conditions. Nurses often assume the predominant role of gatekeepers to the healthcare delivery system for many devalued individuals. Often, clients with chronic illnesses receive effective and efficient care from these nurses and other healthcare professionals, who have great opportunities to perform the role of the wise.

Evidence-Based Practice Box

This chapter has dealt primarily with adults' perceptions of stigma and interventional strategies that healthcare providers can use to both raise awareness of and to decrease the incidence of stigma. The aging of the population in the United States and the continuing negative perceptions surrounding mental illness are addressed in the *Healthy People 2020*

document. One goal is to improve the health and well-being of our elder members through such methods as screening, diagnosing, and treating mood disorders.

A study by Conner and colleagues (2010) offers some insight into the impact of stigma and race on elders seeking treatment for depression.

Purpose: To explore the impact of stigma (external and internal) on treatment-seeking behaviors of older adults with depression by race (African American, Caucasian).

Sample: A random sample of African American and Caucasian adults ($n = 248$) aged 60 years and older (mean age = 72) with mild to moderate depressive symptoms as identified by the Patient Health Questionnaire-9.

Method: Participants were surveyed via telephone to assess treatment-seeking attitudes and behavior and related factors. Perceived external (public) stigma was measured using a revised Perceived Devaluation Discrimination Scale. Internalized stigma were measured using the Internalized Stigma of Mental Illness tool. Attitudes toward mental health treatment were measured using a researcher-modified Attitudes Toward Seeking Professional Psychological Help Scale. Intention to seek treatment was measured by one item using a Likert-type scale. Chi squares, t -tests, and regression analyses were conducted.

Select Findings: Older adults who were depressed perceived more external stigma and were less likely to seek treatment.

(continues)

There were no statistically significant differences noted by race. A statistically significant difference was found for treatment. African Americans were significantly less likely ($X^2 = 11.1$, $df = 1$, $p < .0001$) to have received mental health treatment. African American elders reported more internal stigma ($t = -2.18$, $p = .04$) and held less favorable attitudes toward seeking treatment than Caucasians. A higher degree of internalized stigma was correlated ($r = .136$, $p < .05$) with intention to seek treatment. Regression analyses indicated that “internalized stigma partially mediated the relationship between race and attitudes toward treatment” (p. 538).

Conclusions: Perceptions of stigma negatively influenced treatment-seeking behaviors for all older adults with depression. All participants perceived high levels of public stigma. Strategies to reduce internalized stigma for African American older adults should be implemented in order to improve attitudes toward seeking mental health treatment. Although increased internal stigma was positively related to intent to seek treatment, this may be due to the individual’s depressive symptoms and perceived need. Implementing interventions to reduce internalized stigma for older adults should be individualized.

Source: Connor, K. O., Copeland, V. C., Grote, N. K., Koeske, G., Rosen, D., Reynolds, C. F., et al. (2010). Mental health treatment seeking among older adults with depression: The impact of stigma and race. *American Journal of Geriatric Psychiatry*, 18(6), 531–543.

Another strategy healthcare professionals can use to acquire real-life knowledge about individuals with a particular illness is to increase their interaction with people who have the disorder (Heijenders & Van Der Meij, 2006). In addition to increasing exposure to and interaction with people who have a particular stigmatizing condition, Corrigan and Penn (1999) suggest that it is important for healthcare professionals to be exposed to people who are successfully coping with a condition; those who have recovered from mental illness, who are in remission, or who have been successfully rehabilitated. This knowledge can enable them to offer not only sensitive understanding and practical suggestions to individuals with chronic illness, but also hope. Nurses who work with HIV/AIDS clients, for instance, have the opportunity to find out which behavior is really effective and can learn about outcomes and clients’ reactions. This information is extremely valuable as providers advocate for similar clients and their families.

Implications for Professional Education

Healthcare professionals’ attitudes are representative of general societal views and so can be expected to include prejudices. Because healthcare professionals have prolonged relationships with chronically ill individuals, the impact of these prejudices can be great. Programs to teach professional staff to identify and correct preconceived and often subconscious notions of categories and stereotypes deserve high priority (Dudley, 1983).

Providing intensive staff education for the purpose of reducing stigma perception by all employees in any particular agency is beneficial. In addition, professional staff are then in a

position to role model desired behaviors and to share information to help nonprofessional staff treat clients in an accepting manner.

One study of stigma-promoting behaviors provides ideas for healthcare professionals who wish to change their attitudes (Dudley, 1983). In Dudley's study, the most frequent stigma-promoting behaviors included the following: staring, denial of opportunities for clients to present views, inappropriate language in referring to clients, inappropriate restrictions of activities, violation of confidentiality, physical abuse, and ignoring clients. In-service days that focus on both didactic presentation of communication strategies and role-playing—specific scenarios would be a first step to eliminating situations of enacted stigma in the workplace.

One way to increase visibility and heighten awareness about the impact of stigma is to encourage structured contact between healthcare professionals and affected individuals (Joachim & Acorn, 2000). This approach should be preceded by group work with a knowledgeable leader who can help identify and work through attitudes and reactions. For example, many nursing students do not like skilled nursing facilities (SNFs) because older adults are seen as unappealing. A gerontology nurse specialist spent time with such a group of students before they began working in the SNF. She showed slides of faces etched with character and told stories of interesting experiences these individuals had that helped the students see the elderly as human beings. A group discussion between the specialist and students confronted myths and stereotypical thinking regarding the stigma of aging. As a result, these students had a more positive experience at the SNF.

Knowledgeable preparation for contact with stigmatized individuals does not solve all

problems; it is, however, one way to expose stigmatized reactions such as stereotyping, to examine them, and to provide information to caregivers. The group sessions described here may be appropriate for both nonprofessional and professional caregivers in the community or in agencies.

Implications for Community Education Programs

Educational programs that reduce the effects of stigma can be shared with the community at large. Many organizations, such as the American Cancer Society and the American Diabetes Association, provide speakers or literature for the community. Schools, scout troops, and church groups are ideal settings for sensitive introductions of individuals who have many positive values and characteristics but do not meet normal health expectations. For instance, individuals with HIV/AIDS have been the focus of group discussions in which children learn to see these people simply as other human beings. Educational programs, such as those that dispel the fears about mental illness, reduce the stigmatizing effects of that disease (Link et al., 1989).

Much of the stigma attached to chronic conditions still pervades society's attitudes and policies (Herek et al., 2003); yet, situations have changed. In the 1970s, an unprecedented and multilayered surge of activism grew among individuals with disabilities and their advocates and resulted in significant social and structural change. Individuals with disabilities began to speak out by publishing magazines, creating films, and organizing political action on both the local and national levels. Their actions greatly influenced a landmark change, namely, the Americans with Disabilities Act (ADA), which was signed into law in 1990. This legislation requires the government and the private

sector to provide disabled individuals with opportunities for jobs and education, access to transportation, and access to public buildings.

The media can also be influenced to present a more positive portrayal of people with chronic conditions. Providers and others can write to television networks that show individuals with disabilities functioning well and commend them for these portrayals. Likewise, people can be encouraged to voice their displeasure and to point out inaccuracies surrounding chronic conditions. In late fall 2010, the National Alliance on Mental Illness called for individuals to write and email a major television network and a popular television show's producer over a disparaging, stereotypical portrayal of a historical figure's mental illness.

Mass media campaigns designed to increase awareness of certain conditions or risk factors for disease can backfire in terms of preventing or reducing stigma. Clients with lung cancer not only perceived stigma of cancer in general (such as fear of disclosure, financial impact, body image changes, and effects on family and social relationships), but also the stigma that is associated with smoking and the shame of a self-inflicted disease, regardless of whether they stopped smoking or had never smoked. They experienced fear related to death as depicted by the mass media, families and friends avoiding contact, and being looked upon as being "dirty" in relation to smoking (Chapple, Ziebland, & McPherson, 2004).

Another study identified methods of health communication that were designed to increase public awareness but actually had the opposite effect of increasing public stigma (Wang, 1998). The health communication approaches conveyed individuals with obvious disabling

characteristics with the accompanying message, "Don't be like this." Awareness was heightened at the expense of furthering the stigma of the disabled individual. Healthcare professionals who volunteer to serve on executive boards of healthcare agencies or support agencies can offer guidance to those developing marketing campaigns, public service announcements, and community education materials.

Recent social changes have suggested that internalization of stigma based on prevailing social norms may be changing for some health problems. Rehabilitation programs for substance abuse are now commonly covered by health insurance, in part as a result of active consumer demand, evidencing a change of social attitude (Garfinkel & Dorian, 2000). The impact of stigmatizing conditions in women's health, such as abortion and breast cancer with mastectomy, has been reduced (Bennett, 1997). These changes are, perhaps, evidence that visibility and disclosure may have a positive impact on the process of negative stereotyping.

OUTCOMES

Determining client outcomes, like many of the psychosocial concepts associated with chronic illnesses, is difficult. Some clients may be stigmatized on a regular basis but have been able to overcome the personal feelings associated with it. Therefore, client outcomes of stigma might be the *lack* of other common psychosocial effects of chronic illness. For example:

- The client is *not* socially isolated, but is continuing his or her daily and normal activities without difficulty.

- The client's self-esteem remains high despite the chronic illness and accompanying physical symptoms.
- Healthy relationships continue with family, friends, and supportive others.
- The client is *not* depressed and interacts appropriately with others.

STUDY QUESTIONS



Compare and contrast the concepts of felt stigma and enacted stigma. Are these two concepts mutually exclusive?

How does the process of labeling by others influence the perception of felt stigma and the incidence of enacted stigma?

Advanced practice nurses can implement strategies to decrease the incidence of enacted stigma in society. What might the advanced practice nurse do in each of the following roles to decrease stigma: nurse administrator, nurse educator, clinician?

As a change agent in your practice setting, what strategies can you readily implement to increase awareness of stigma among administrators, healthcare professionals, and support staff?

What strategies can you readily implement to decrease the perceptions of stigma by your clients?

Discuss the similarities and differences among prejudice, stereotyping, and labeling. What is the relationship to stigma?

INTERNET RESOURCES



Resources

Mental Health Issues

Achieve Solutions website: <https://www.achievesolutions.net/achievesolutions/en/tlc/Content.do?contentId=21466>

U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration stigma homepage: <http://www.whatadifference.samhsa.gov/>

Stigma.org links to mental health websites: www.stigma.org

Active Minds: Changing the Conversation on Mental Health (working to reduce the stigma of mental illness on college campuses): www.activeminds.org

National Alliance on Mental Illness Stigma Busters (click on Fight Stigma to sign up for StigmaBusters alerts and to access resources): www.nami.org

HIV/AIDS Issues

HRSA Care Action—Providing HIV/AIDS Care in a Changing Environment: hab.hrsa.gov. Resources include a literature review on HIV and stigma, clinical guidelines.

HIV & AIDS: Stigma and Discrimination: <http://www.avert.org/hiv-aids-stigma.htm> (Note: Avert.org is also available on Facebook.)

For a full suite of assignments and additional learning activities, use the access code located in the front of your book and visit this exclusive website: <http://go.jblearning.com/lubkin>. If you do not have an access code, you can obtain one at the site.



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