الخبرةالذاتية للوصمة وإستراتيجيات التكيف معها بين المرضى النفسيين

رسالة علمية

مقدمة إلى الدراسات العليا بكلية التمريض

جامعة الأسكندرية

استيفاء للدراسات المقررة للحصول على درجة

الماجستير فى العلوم التمريضية

فى

التمريض النفسى و الصحة النفسية

مقدمة من أميرة محمد على على

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لجنة المناقشة والحكم على الرسالة **موافقون**

الأستاذة الدكتورة/ سناء عبد العزيز إمام .....

الأستاذة الدكتورة/سامية محمد عبد الدايم .....

الأستاذة الدكتورة/سها عبد اللطيف أجمد .....

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لجنة الإشراف

الأستاذة الدكتورة/ سناء عبد العزيز إمام .....

الأستاذالمساعدالدكتورة/ علا أحمد لاشين .....

INTRODUCTION

Mental illness strikes with a two-edged sword. Patients with mental illness have been stigmatised, devalued and discriminated against for centuries (1, 2). Although, mental illness has been identified as a leading cause of disability; yet stigma associated with mental illness has been found to be much more disabling and debilitating than the disease its self (2). Stigma is defined as ‘a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons’(3)

Several studies reported widespread of negative, discriminatory and marginalizing attitudes against persons with mental illness. Patients are portrayed as incompetent, unexpected, disturbed, dangerous, aggressive and unable to care for themselves and deserve to be segregated to protect others from harm (4, 5). There is evidence that public’s negative attitudes, avoidant behaviours and desire for social distance from persons with mental illness have increased lately. The public’s limited understanding of mental illness was gained from news and entertainment media which overwhelmingly promote associations of mental illness with crime, violence and bizarre events. Media-fed stereotypes and the fact that mental illness is hidden and not talked about have contributed to mental illness being seen as uncommon and scary (6, 7).Unfortunately, such negative attitudes and stereotypes don’t only exist in the public but extend to the mental health professionals themselves (5). Stigmatizing treatment by health care givers for people with mental illness as being less competent discourages patients from setting high goals (8).

Stigma and discrimination resulting from societal reaction to severe mental illness has been recognized as a major confounding problem (3, 5). The negative perception of mental illness not only reinforces the stigma but also impairs the patient’s quality of life. It unjustly impedes the person with psychiatric disability from attaining work, good housing, affiliation, and other independent living opportunities. This consequently interferes with achieving many social roles and formal statutes that prevent a patient from marrying and having children (5, 9).

Introduction

The impact of social exclusion, rejection, high stress due to stigma includes persecution, isolation, loss of social support, not seeking medical help, reduced access to care, lack of compliance with treatment, poor recovery, fear of discovery, worries, and frustration (3). Misunderstanding, myth, fear and the resulting stigma and discrimination surrounding mental illness often force people with this disorder in developing countries to get alternate traditional treatments such as the Zar cult. This delay in getting proper treatment for mental illness may result in further deterioration of the condition, more chronicity and overburdened health care system as they turn to the health system at the end of the journey when all trials of traditional healers fail (6, 10, 11).

People with mental illness reported being severely limited in their social life because of fear of discrimination and ostracism from the community (12). It is reported that stigma experience has a variety of long-term consequences and lasting effects. Such reported consequences include lowered self-esteem and loss of confidence in self. The experience makes patients less likely to disclose information about their disorders as they often find that they are treated differently, often negatively; it is especially an issue for employment. They become more likely to avoid social contact, and less likely to apply for jobs or educational opportunities. In addition, lasting effects of stigma on patients' feelings about and expectations of others, indicate that their experiences contribute to their being less trusting of others, more guarded, and more sensitive to slight. To a large extent, it was also reported that their stigma experiences also contribute to the persistence of symptomatic emotions such as anxiety and depression (8, 13).

Families touched by mental illnesses often feel profoundly affected by stigma associated with the disease, as well as by feelings of guilt and shame (14, 15). People tend to hide the fact that they have a relative with mental illness in the family from others in order to protect the family's name and reputation from being stigmatized or discriminated against by friends and neighbours because of mental illness. In addition, Egyptian families with members affected by mental illness fear to be seen as having bad blood i.e. having a genetic factor of mental illness and, therefore, will be inherited in the

coming generations. This in turn will put their daughters at risk of not being married (6, 10).

Mental health nurses should take the role as advocates, not only for the profession of mental health nursing but most importantly for the consumers of mental health services. They need to be aware of possible influences on belief systems about mental illness. They need to have sufficient understanding of the meanings that may be attributed to mental illness and its treatment and the meaning that may be attributed to family and relationships outside of family. They must continually challenge the discriminatory attitudes of the public and general health professionals and either subtly or overtly influence them towards the development of more open and inclusive attitudes (1, 4, 10). People with mental illness express feelings of relief when others are supportive and sympathetic towards their illness. Therefore, mental health nurses should maintain optimism in helping their patients to cope with the stigma (16).

Less is known about the actual stigma experiences of persons with mental illness and their family members. Even more, the attitudes and experiences of consumers themselves have been the focus of limited investigation (17). This study has the potential of helping mental health nurses to gain a deeper understanding of stigma and of the negative consequences associated with. As a result, nurses can contribute to improving the attitudes towards, and the quality of services for the consumers of mental health services. To the researcher's knowledge, little research has been conducted on this aspect in Egypt. This highlights the need for systematic and comprehensive investigation of subjective experience of stigma among patients with mental illness and their coping strategies.

The research question answered by the current study is: "Do people with mental illness experience and cope with stigma?".

At the same time this study aims to:

1. Identify the subjective experience of stigma among patients with mental illness.
2. Determine mental patients' ways of coping with such stigma.

REVIEW OF LITERATURE

Historical perspective of mental illness stigma

Fear and shame about mental illness go back for centuries. It may be one of the oldest prejudices (18). In the 17th and 18th centuries, persons with mental illness were considered monsters. Madhouses and torturous somatic treatments became big business. In the 19th century, Phillipe Pinel in France and a group of Quakers in York, England, began to treat patients on the basis of a philosophy of treatment morale that included retreat-like settings, humane and fatherly superintendents, and activities for the patients, and incentives for appropriate behaviour (19-21). Asylums were designed for that purpose but in fact they were considered a residence for the socially troublesome mental patients. Conditions in these institutions were horrible; with no fresh air, no light, and very little nutrition. "Inmates" as they were called were locked up into dark cells, sometimes sleeping five to a mattress on damp floors, chained in place with bars on windows; they were also beaten for misbehaviour much like wild animals (22, 23).

Mental illness appears to be a characteristic that has nearly always led to the stigmatization and exclusion of its victims. There may be evolutionary origins for stigmatization based on the exclusion of persons perceived to be poor social exchange partners and carriers of non-treatable diseases (24). The classical philosopher's definition of a human being as a "rational animal" excluded those who had lost the use of reason and was no longer regarded as fully human. This notion was summarized in the well-known saying of Lucretius, "Whom the Gods wish to destroy, they first make mad" (25).

The *early* 20th century witnessed massive rejection and discrimination against people with mental illness (21, 26). Such stigmatization of the mentally ill has led to punitive state responses to mental illness and gross crimes against humanity such as the eugenics movement during the 1900s to 1940s, which was implemented in countries including Germany, USA, and Britain, involved various programs of compulsory sterilizations and euthanasia targeting individuals with mental illness mainly those suffering from schizophrenia and bipolar disorder. They were considered “useless eaters”

and “social wastage” that could be denied basic human rights. Knowledge of this history could to be extremely damaging to the self-esteem of individuals with mental illness and their families (21, 27, 28). In China, where history and culture value the needs of, and benefits for the community over the needs of, and benefits for the individual; eugenic programs have been initiated to prevent new births of inferior quality. By law, marriage where one or both parties have schizophrenia or bipolar disorder is to be postponed until the illness is resolved. Even then, childbirth is forbidden (28, 29).

Despite the great advances in psychiatric treatment and the evolution of psychotropic medications that the second half of the 20th century witnessed; stigma didn’t improve much (30). Still today, in many parts of the world, mental illness is related to mystical beliefs and supernatural views such as witchcraft, spiritual or demonic possession and evil eye. Therefore, people with mental illness were feared and kept shut away, out of sight (10, 19, 31-33).

What is Mental Illness Stigma?

Stigma is a central problem encountered by individuals with mental illness which is usually chronic in nature (34, 35). The term "stigma" has a historical context. Stigma is a Greek word that in its origins referred to a kind of a branded mark or a tattoo that was cut or burned into the skin that signifies something undesirable about the bearer of the mark. It was used mainly for criminals, slaves, or traitors in order to visibly identify them as blemished or morally polluted persons. These individuals were to be avoided or shunned, particularly in public places (25, 36-39). Stigma has been defined in several ways based on different perspectives; with some emphasising difference, some emphasising social norms, some emphasising the impact of stigma on individuals; while others were made collectively. The following are the reviewed definitions:

A- Stigma definition according to difference

Erving Goffman (1963) was the first one who defined stigma as an undesired differentness’ proposing that people are stigmatised when they possess a ‘significantly discrediting’ attribute through which a stigmatized person is reduced ‘‘from a whole and usual person to a tainted, discounted one’’ (40-42). In spite of definition change several

authors agree with Goffman that stigma is a “shared negative evaluation of human differences” (43), or "the process of labelling or branding, or the process of developing the signs or traits that appear to justify being labelled or branded, or singled out" (32), or “a token of disgrace, a taint, a blemish, a blot on one's good name” (40, 41, 44).

B- Stigma definition according to social norms

Recently, social psychologists defined stigma more in terms of a person’s ‘social identity’. They described the stigmatizing process as relational, i.e. the social environment defines what is deviant and provides the context in which devaluing evaluations are expressed. Jones et al. (1984) emphasizing Goffman’s idea of stigma as an attribute, use the term ‘‘mark’’ to describe a deviant condition *identified by society* that might define the individual as flawed or spoiled. This definition adds to Goffman’s definition that stigma is not located entirely within the stigmatized person, but occurs within a social context that defines an attribute as devaluing. In other words stigma is clearly culturally dependent, varying with both time and place (41). Many agree with Jones et al. such as Scott and Stafford (1986) who proposed stigma as a characteristic of persons that is contrary to a norm of a social unit. A norm being, in their definition, is a shared belief that a person ought to behave in a certain way at a certain time (40, 43). Emphasising on role of culture, Coleman (1986) defined stigmatization as a set of responses to undesired differences that leads to some restriction in physical and social mobility and access to opportunities that allow an individual to develop his or her potential (45).

C- Stigma definition according to impact on stigmatized persons

Stigma defined as having undesirable attributes that mark people as different carries massive consequences of external social exclusion, prejudice and discrimination as well as internal secrecy, lowered self-esteem and shame (40, 41). Clausen (1981) adopting this view, described stigma as a buzz word, arousing more emotional reaction than words like devaluation and discrimination" (45).

D- Collective definition of mental illness stigma

Link et al. (1997) defined stigma as undesirable characteristics linked to mental illness that lead to a cluster of adverse cognitive and behavioural consequences including

negative attitudes and beliefs that motivate the general public to fear, reject, avoid, and discriminate against people with mental illnesses, robbing them of the opportunity to live, work and thrive in the community (46, 47). Individuals suffering from mental illness are usually seen as a diagnosis not as human beings (35).

Theoretical Perspectives of Mental Illness Stigma

There are many theories that explain the formation of negative attitudes towards persons with mental illness and the effects of such attitudes on patients. These theories have greatly advanced the understanding of how an individual's stigmatized social identity is constructed through cognitive, affective and behavioural processes (5). Social stigmatization of psychiatric patients has its sociologic roots in theories of labelling and deviance (48).

A-Labelling Theory

Labelling theory developed by Scheff (1966), describes mental illness with regard to reactions of others to "residual rule-breaking" which is violation of feelings or expression norms (49). It explains social control processes and their consequences by elaborating on the relationship between deviating activities and the organized social responses which identify, label, and control such deviations (50). It states that labelling person's behaviours as "mental illness" triggers negative stereotypes such as dangerousness, leading to social rejection and changes in identity, ultimately fostering "careers" in "residual deviance." It assumes that the official label through treatment contact rather than the behaviour per se shapes the fate of mentally ill persons, by creating chronic mental illness or by compromising the life chances of those so labelled (41, 51).

Labelling theory holds that devaluation and discrimination attached to the label perpetuate mental illness and interfere with a broad range of life areas, including access to social and economic resources and general feelings of well-being. Uniform responses from others such as social exclusion block labelled mentally ill's attempts to return to ''normal'' social roles, even, they are "punished when they attempt to return to normal roles" (41, 52). Thus application of deviant labels to individuals leads to low levels of

perceived mastery and self-esteem that in turn compromise subjective quality of life by producing a sense of hopelessness and a tendency to give up in difficult times (34).

B- Modified Labelling Theory

Labelling theory received a lot of criticism regarding how such described negative consequence of stigma occur. It was said that labelling and stigma are unimportant and such consequences the mentally ill patients suffer from are related directly to the pathology not to the label. Modified labelling theory was developed by Link et al (1989) to describe the stigmatizing process and the dynamic by which negative consequences occur. It notes that stigma operates primarily in the social sphere. It postulates that the label of "former mental patient" is a stressor that increases symptoms and elicits strong expressions of social distance. It suggests that the stigma of mental illness is problematic because it damages mental patients' sense of self-esteem and self-efficacy (34, 53).

Once labelled, an individual is subjected to uniform responses from others. Individual's behaviour crystallizes in conformity to responses and expectations of others and is stabilized by a system of rewards and punishments that constrain the labelled individual to the role of a "mentally ill person." When the individual internalizes this role, incorporating it as a central identity, the labelling process is complete and chronic mental illness is the consequence. Patients reorganize their views of themselves and their self knowledge in terms of what they are not and cannot do rather than what they are and what they can do. Thus, people with chronic mental illness often experience a profound sense of loss of the characteristics they valued in themselves and of cherished life goals and assumptions. The damage to these assumptions and ideals is seen as the basis of demoralization and by extension, such damage affects subjective quality of life (34, 53).
This theory explains labelling process and its consequence through five distinct steps which are:

Step 1: Beliefs about devaluation and discrimination:

In the course of being socialized, individuals learn the attitude of the community toward the mentally ill through a variety of mechanisms including jokes, cartoons, and the media's reporting of mental patient status that can influence views of what it means to be mentally ill. All members of society-those who will become psychiatric patients as

well as those who will not; develop negative conceptions of what it means to be a mental patient and thus form beliefs about how others will view and then treat someone who acquires that status (2). Typically this set of beliefs is fully in place before an individual enters treatment. As a result, when patients enter treatment for the first time, they are likely to confront the effects of stigma immediately because often they have internalized a generally negative view about what it means to be a mental patient (53).

Step 2: Official labelling through treatment contact:

Once official labelling occurs during contact with treatment, expectations of devaluation become personally relevant and applicable to oneself; it now matters whether one believes that people will devalue and discriminate against a person who is in treatment for mental illness. Social sanctioning processes in the form of devaluation-discrimination may alter social and self-identities. Official labelling makes patients' beliefs about devaluation-discrimination personally relevant and activates coping strategies such as secrecy, withdrawal, and advocacy or confrontation (41, 50, 51, 53).

Step 3: patients' responses to their stigmatizing status:

Mental patients try to overcome the stigmatizing effect of a label by constructing strategies and schemes for social interaction or by engaging in cognitive exercises designed to cast their situation in a different light (52). There are three possible responses to labelling and a tendency to endorse them indicates that patients see stigmatization by others as a threat. In the first, secrecy, patients may choose to conceal their treatment history from employers, relatives, or' potential lovers to avoid rejection. Second is withdrawal, or limiting social interaction to those who know about and tend to accept one's stigmatized condition. Third is the attempt at educating others "preventive telling" in hopes of enlightening them so as to ward off negative attitudes (34, 53).

Step 4: Consequences of the stigma process on patients' lives:

Negative outcomes may arise directly from one's beliefs about community attitudes toward the status of mental patient, or they may follow from attempts to protect oneself by withdrawing. If people believe that others will discriminate against them or devalue them because of a status they possess, powerful and unfortunate consequences can ensue. They may feel shame or believe that they are set off from others and thus are

very different. In addition, it can negatively affect social interaction and self-esteem or even increase vulnerability to future psychiatric relapse (41, 45, 52, 53).

While adoption of secrecy, withdrawal, and education may protect patients from some negative aspects of labelling, they also may limit their life chances. For example, withdrawal may lead to more constricted social networks and fewer attempts at seeking more satisfying, higher-paying jobs. This is consistent with the classical labelling theory idea of secondary deviance with its emphasis on "defence, attack, or adaptation" to factors brought on by labelling (52).

Step 5: Vulnerability to future disorder:

As a consequence of labelling and subsequent reactions of others, patients lack self-esteem, social network ties, and employment. These deficits are regarded as major social and psychological risk factors for the development of psychopathology and exacerbation of pre-existing mental disorders (41). Thus, for some patients, labelling and stigma may induce a state of vulnerability that increases their likelihood of experiencing repeated episodes of disorder (51, 53).

C- Social Identity Theory

Based on Scheff's work, Thoits (1985) developed social identity theory which suggests that self-conception emerges from, and is sustained in social relationships. One's sense of self as a meaningful object arises from taking the role of specific and then of the generalized others; i.e. an individual sees himself as a kind of person from the eyes of primary others and the community. It postulates that persons are constituted by the process of interactively validating a self identity within ongoing activities which are themselves shaped by social structures of available or appropriate identities (49, 50). According to this theory there are three successive assumptions that explain self labelling as an identity taking process. These assumptions are:

1- Individuals who will self-label are well socialized actors as they share the cultural perspectives of the larger society about violated norms or the deviant condition "here it is mental illness". In other words, they recognize public's beliefs and reactions to people with mental illness.

2- Acquiring mental illness forces affected persons to belong to a known category of violated norms; and consequently they carry cultural labels "crazy or mentally ill" that can be applied to such category by oneself or by others.

3- In the self-labelling process, the actor is motivated to conform to social expectations as they suffer from reward deprivation and punishment for they are mentally ill (49). Those who internalize stigma and experience social rejection may adopt social withdrawal and suffer from lowered social and economic well-being as a form of self fulfilling prophecy (41, 51, 54). Socio-culturally produced labelling effects lead patients to outward behavioural manifestations that mimic personal incompetence; these can be interpreted in turn as the patient's private failing-part of what is "wrong" with him or her. Accordingly, a social problem is inappropriately transformed into an individual trouble (52).

D- Attribution Theory

Attribution theory developed by Weiner (1995) is a model of causal attribution which holds the assumption that behaviour is determined by a cognitive-emotional process (55). People have an intrinsic need to understand the cause of events around them; they make attributions about the cause and controllability of a person's illness that lead to inferences about responsibility. These inferences lead to emotional and behavioural responses such as anger or pity that affect the likelihood of helping or punishing behaviour (5, 51, 56).

According to Weiner, people use discriminatory stimuli or cues that signal stigma. Such stimuli are either discredited with a readily manifest mark as skin colour or discreditable with no manifest mark that represent blemishes of individual character as mental illness that one can hide, as people don't know if the person is mentally ill by looking at him (24). They know from the labels such as being seen coming out of a psychiatric mental health office, psychiatric symptoms as inappropriate affect, bizarre behaviours and/or talking to self aloud, social skill deficit such as deficit in eye contact, poor personal hygiene and the like (5, 57).

The meaning of discriminatory signals is translated into stereotypes which are considered cold cognitive appraisal; but they are efficient because people can quickly generate impressions and expectations of individuals who belong to a stereotyped group

(51). If people agree with stereotypes they develop prejudice which is a hot emotional response to out-groups ignoring their personal merits. Attribution theory suggests that the emotional and behavioural responses are associated with controllability and responsibility attributions about causes of mental illness (5, 24). When people are presented with an event or situation such as "a person with mental illness," they try to determine who is responsible. Persons not believed to be in control of negative events (their symptoms) are more likely to be pitied by others; and others may be willing to help. Persons viewed to be in control of negative events (their symptoms) are more likely to be held responsible and reacted to angrily in a punishing manner; and may be unwilling to help (5, 42, 51, 55, 58).

Types of Stigma

Stigma is a dynamic process composed of three main elements: the perceiver or stigmatizer, the stigmatized and the social interface which is affective cognitive-behavioural dimension of the process. The stigmatized person himself can become self stigmatizer under certain conditions (59). Depending on the nature of stigmatizers, stigma is classified into two broad types *Public Stigma* and *Self Stigma* (45, 56, 60).

[1] Public stigma

Public Stigma is defined as a phenomenon of a large social group endorsing stereotypes about and acting against a stigmatized group, people with mental illness in this case (3, 45, 55, 56, 60). The Experience of Public Stigma against an Out-Group is composed of a set of cognitive and behavioural structures (61-63). Link & Phelan, 2001 described stigma as a process composed of 4 interrelated components namely: labelling someone with a condition, stereotyping people who have that condition, creating a prejudice and discrimination (62, 63).

A- Labelling someone with a condition

The process of labelling involves two main items which are the condition or attribute that is deemed salient by society, and associating such attribute to individuals that can be grouped together according to some socially relevant human difference (5, 37, 41, 62, 64, 65).