Maturity Level of the Stigma Concept Associated with Cancer Diagnosis in the Nursing Literature

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Abstract

Objective: This study aimed to evaluate the maturity level of stigma as a concept in nursing and its relationship to care provided for patients with cancer. Methods: The four principles of Morse and his colleagues were used to evaluate the maturity level of the stigma concept: epistemological, logical, pragmatical, and linguistic. Analysis was conducted with the literature published between 2006 and 2016. Results: The findings of this study suggest that the concept of stigma in nursing is immature, defined inconsistently, and measured with different instruments. How stigma is defined can influence nurses in their assessment of patients with cancer and identification of their needs. Conclusion: Although extensive studies have been conducted in the field of mental illness, it is only recently that the effect of stigma on treatment of cancer patients has attracted attention. Thus, substantial work yet needs to be done to understand the breadth and scope of stigma impacting on individuals with cancer.

Keywords: Stigma- cancer- concept analysis- maturity level- nursing

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Introduction

Stigma has a negative influence on individuals' health, creating social distance, which affects their interactions with people in the society (Lebel and Devins, 2008; Ahmad and Dardas, 2016). Nursing concepts have different levels of abstraction (Waltz et al., 2010). The negative influence of stigma on people’s lives creates a negative self-concept and causes individuals to be socially distant from the society (Parcesepe and Cabassa, 2013). The concept of stigma has been well-documented in literature and it was frequently related to people who suffer from specific health problems such as cancer, Human Immunodeficiency Virus (HIV), mental illness, and disabilities (Copel and Al-Mamari, 2015).

How stigma is defined or understood is important for health care professionals, patients, and general population. Literature and research address the influence of stigma on diseases; however, systematic concept analysis is still insufficient to identify the maturity level of stigma as a concept (Copel and Al-Mamari, 2015, Parcesepe and Cabassa, 2013).

Definitions of Stigma

Stigma as a term goes back to the ancient Greece where criminals, slaves, and traitors were identified by using tattoos on their bodies. People with illness or abnormal behaviors have been socially discriminated and avoided (Engebretson, 2013). Later in Christian time, the word “stigma” was used in the interpretation of bodily physical features as an indicator either for holy grace and/or physical disorder (Goffman, 1963). Furthermore, stigma was used in medical texts to refer to pathological markings of the skin such as petechia or lesions that are associated with specific diseases (Weiss et al., 2006). The English Oxford dictionary (2016) defined stigma as “Feelings of disapproval that people have about particular illnesses or ways of behaving.”

Goffman (1963), who is a well-known sociologist defined stigma as “the phenomenon whereby an individual with an attribute which is deeply discredited by his/her society is rejected as a result of the attribute. Stigma is a process by which the reaction of others spoils normal identity” (Lim and Tan, 2014). Goffman considered stigma as a relation between attribute and stereotype where the stigmatized person is moved from the normal and usual to the deviant and discounted one, also identified three types of stigma, body (physical), character (personal), and tribal (social). Goffman’s efforts are considered as seminal work and has inspired research on stigma in social science and social psychology (Omori et al., 2014; Dardas and Ahmad, 2015).

Link and Phelan (2006) claimed that increasing social science research on stigma, especially in social psychology leads to individualization, inconsistency and many variations on the definition of stigma. Link and

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Phelan (2006) constructed a definition of stigma as “the co-occurrence of its components—labeling, stereotyping, separation, status loss, and discrimination—and further indicate that for stigmatization to occur, power must be exercised” (Link and Phelan, 2001).

**Stigma and Cancer**

Cancer is associated with stigma, due to misunderstanding and myths around cancer (Ahmad and Al-Gamal, 2015). Hence, cancer patients often do not share the diagnosis of cancer when looking for work as it affects their physical abilities. Furthermore, there are taboos and cultural beliefs about cancer patients. Cancer is viewed by certain communities as a punishment or as a contagious illness; these myths might increase the risk of stigmatization and social isolation against this population (Ahmad and Al-Gamal, 2015; Knapp et al., 2014). Another contributing factor that causes stigma is the belief of the patients themselves that their behaviors could contribute to the development of cancer. Voluntary engagement in such behaviors, like smoking, overweight, sedentary life were perceived by the patients as causes of their illness, hence increasing the sense of stigma among them (Lebel and Devins , 2008). Increased knowledge in society about the nature of cancer, its types and treatments, and its complications would help in decreasing the cancer related stigma (Ahmad and Al-Gamal, 2015). In addition, patients with cancer may seek out support for their cancer type and to be surrounded with positive people (Rayan and Jaradat, 2016).

The purpose of this paper was to evaluate the maturity level of stigma concept mainly with cancer diagnosis by adopting the four principles of Morse et al., (1996) in concept analysis: epistemological, logical, pragmatical, and linguistical.

**Stigma in Nursing Discipline**

The concept of stigma in nursing literature remains unclear (Florom-Smith and Santis, 2012). Inconsistency in conceptual and operational definitions was reported throughout the literature (Ahmad et al., 2016; Oliveira et al., 2016; Kato et al., 2014; Zelaya et al., 2012). Most of the nurses based their derived definitions of stigma on the work of Goffman (Pinto-Foltz and Logsdon, 2008). Most of the nurses based their derived definitions of stigma on the work of Goffman (Pinto-Foltz and Logsdon, 2008). This indicates lack of a specific definition of stigma concept in nursing.

Some nursing studies have focused on stigma as a general attribute, while other studies have elaborated on the different types of stigma. Furthermore, some studies were inconsistent when they referred to the types of stigma (Oliveira et al., 2016; Omori et al., 2014). Examples of definitions of Stigma concept in nursing discipline are presented in Table 1.

**Materials and Methods**

The evaluation of the maturity level of stigma as a concept in nursing discipline was guided by the four principles recommended by Morse et al., (1996); epistemological, logical, pragmatical, and linguistical. stigma-related literatures were retrieved by searching the cumulative index to nursing and allied health literature (CINAHL), Ebsco, MEDLINE, and Google Scholar. Search terms used were: stigma, cancer, health-related stigma, concept analysis, stigmatization, social identity, social support, chronic illness and nursing. Initial search was restricted to include published literatures from 2006 to 2016 with full text and presented in English. Some literatures before 2006 were also considered since it included seminal studies and definitions.

**Results**

**Epistemological**

The first premise in the principle-based concept analysis method refers to the examination of the concept, whether it is clearly identified and well distinct from other concepts in order to be evaluated as a mature concept (Penrod and Hupcey, 2005). Previous studies in the psychology and the social sciences have extended to Goffman’s theory to reveal about the nature, sources and consequences of stigma in order to investigate the wide variation in defining and conceptualizing the concept of stigma (Brinkley-Rubinstein, 2015; Engebretson, 2013; Omori et al., 2014). Stigma as a concept remains uncertain due to the diverse stereotypes and interactive characteristics that belong to the different health conditions among minorities Omori et al., (2014). Furthermore, concept of stigma was often discussed in separation from its multiple forms and intersectional exploration, thus, leading to a substantial burden that there is no consensus in the literature on what the definition of stigma constitutes (Brinkley-Rubinstein, 2015). It is important to highlight that the meanings of stigma change across cultures or over time. For instance, epilepsy has been perceived as demon possession, a neurological disorder, as well it was perceived as a spiritual gift from God in the book “The Spirit Catches You and You Fall Down” which illustrated the contradictory between the Hmong culture and the American culture (Fadiman, 1997). Link and Phelan (2006) Reported that stigma was constantly changing trajectory of human being behavior. Thus, definitions of stigma vary within the context in which it is studied.

Distinction of stigma concept from its various standpoints like its nature, sources, reasons and consequences of an episode in the lives of people is a matter of a challenge (Link and Phelan, 2006). Hence, stigmatized individuals have been recognized to have several negative attributes, and subsequently they are treated differently by society members (Link and Phelan, 2006). It is crucial to review the uncertainty in conceptualizing the concept of stigma and its impact on the individuals’ conditions. Therefore, a comprehensive understanding of the complexities linked with the sociocultural, conditional and structural attributes that influence the experience of stigma should be taken into account for better differentiation of the concept of stigma (Butt, 2008).

Moreover, concepts that are related to stigma have been studied for explanation and measurement. For instance, Self-stigma and public stigma both are related to the concept of stigma but each one of these has been
Stigma is a social process, discrediting and devaluing individuals or groups with an attribute that is either feared or sanctioned by society as immoral or deviant (Engebretson, 2013). Stigma can be both externally imposed and internally perceived as a process of sensemaking (Vogel et al., 2007). Perceived stigma was experienced by participants’ family and children via avoidance by friends and family members because of unfounded fears of infection. Stigma can be classified from attitude, appearance, and even from medical diseases (Green, 2009).

Many psychological studies examined perceived self-stigma, perceived public-stigma, and social distance as common types of stigma (Evans-Lacko et al., 2012; Rayan and Jaradat, 2016; Vogel et al., 2007). Perceived public-stigma is the extent to which individuals expect that other persons will devalue or discriminate against persons who are mentally ill, while social distance scrutinizes individuals’ willingness to communicate with persons who are mentally ill (Vogel et al., 2007). Stigma can be both externally imposed and internally perceived as a process of self-stigma (Engebretson, 2013). Stigma is associated with a negative self-evaluation that may lead to negative treatment and threat for self-identity (Major and O’Brien, 2005). A negative self-evaluation is internalized and may lead to feel of shame or guilt and to the worry of being discriminated by the society because of this health condition (Major and O’Brien, 2005). Stigma is associated was found among patients who had lung cancer; and contributed to psychological distress among those patients (Chambers et al., 2012). Psychological distress that is related to stigma may contribute to higher burden of illness through delayed presentation for care, premature termination of treatment, and the intensification of psychological burden (Heijnders et al., 2006).

Table 1. Definitions of Stigma Concept, and Stigma Types Used in Nursing Discipline

| Author                             | Type of Stigma                | Definition of Stigma                                                                 |
|-----------------------------------|------------------------------|--------------------------------------------------------------------------------------|
| Oliveira, Carvalho, & Esteves, 2016 | Internalized stigma (self-stigma). | The process in which a person internalizes stigmatizing beliefs about mental illness, accepting and applying the negative stereotypes to oneself |
| Zelaya, Siravaram, Johnson, Srikrishnan, Sumit, & Celentano, 2012 | Stigma                        | Is a social process, discrediting and devaluing individuals or groups with an attribute that is either feared or sanctioned by society as immoral or deviant |
| Kato, Takada, & Hashimoto, 2014   | Self-stigma: (internalized stigma) | A stigma that is experienced by individuals who have negative Attitudes towards themselves as a result of their condition And/or characteristics |
|                                   | Public stigma (social stigma) | Represents negative reactions of the general public towards a group Based on stereotypical attributes that distinguish that group in society |
| Florom-Smith & Santis, 2012       | Stigma                        | - Irving Goffman (1963): an attribute or characteristic that is profoundly discrediting to the individual possessing the attribute or characteristic. |
|                                   | AIDS related                  | - Herek (2002): a lasting, negatively valued circumstance, status, or characteristic that discredits and disadvantages individuals. |
|                                   | Stigma (Public Stigma)        | Stigma directed at people living with HIV/AIDS (PLWHA) and/or associated with PLWHA. |
|                                   | Felt stigma (Internalized stigma, self-stigma) | A fear of disclosure of HIV serostatus, in anticipation of resultant discrimination |
|                                   | Enacted stigma                | Discrimination in the forms of rejection, verbal insults, and ostracism perpetrated by family members and friends, and was manifested as avoidance related to fears of infection, judgment, and an inability to understand why spouses or caregivers would choose to remain with people living with HIV. |
|                                   | Courtesy stigma (Stigma by association) | Stigma caused by an association with an individual living with a stigmatizing condition| was experienced by participants' family and children via avoidance by friends and family members because of unfounded fears of infection. |
| Omori, Mori, & White, Self-Stigma in Schizophrenia: A Concept Analysis, 2014 | Stigma | Link and Phelan (2001): the term “Stigma” should be applied “when elements of labeling, stereotyping, separation, status loss, and discrimination co-occur in a power situation that allows the components of stigma to unfold” (p. 367). |
|                                   | Self-stigma                   | Stereotyping, prejudice, and discrimination toward oneself |

examined and explained differently particularly among individuals with psychiatric illnesses Omori et al., (2014). Stereotyping, prejudice, and discrimination are considered as the basic facets for the concept of stigma as well as the self-stigma (Link and Phelan, 2006), whereas, self-stigma characterized by harmfulness to self-identity (Pinto-Foltz and Logsdon, 2008) self-stigma can be resulted from internalized Sociatal stigma Vogel et al., (2007). Many psychological studies examined perceived self-stigma, perceived public-stigma, and social distance as common types of stigma (Evans-Lacko et al., 2012; Rayan and Jaradat, 2016; Vogel et al., 2007). Perceived public-stigma is the extent to which individuals expect that other persons will devalue or discriminate against persons who are mentally ill, while social distance scrutinizes individuals’ willingness to communicate with persons who are mentally ill (Vogel et al., 2007). Stigma can be both externally imposed and internally perceived as a process of self-stigma (Engebretson, 2013).

Logical
The second premise in the principle-based concept analysis method, which refers to the integration of the concept with related concepts. It also determines whether the conceptual boundaries are kept through logical and theoretical integration with other concepts (Penrod and Hupcey, 2005). Stigma is a broad and complex social phenomenon; therefore, several dimensions of stigma were discussed by psychologists to include perspectives of: visibility, course and perceived danger, controllability, and perceived stigma (Green, 2009). Social psychologists conceptualized stigma as the co-incidence of: labeling, stereotyping, separation, and emotional reactions, those often lead to status loss and discrimination (Link and Phelan, 2006). Individuals who are stigmatized are seen as unsafe and scare others, and they are discriminated at their societies (Link and Phelan, 2006). Psychologists concluded that the concept of stigma has conceptual adequacy and relevancy with multiple conditions and circumstances of stigmatized groups (Parker and Aggleton, 2003). It was noted that labeling can be classified from attitude, appearance, and even from medical diseases (Green, 2009).
Table 2. Application of Stigma Concept in Nursing Researches

| Title                                                                 | Author and Year |
|----------------------------------------------------------------------|-----------------|
| The Stigma Scale for Chronic Illness in the Workplace: Stigma, Strain, and meta-strain Using Survey Methodologies | Raymond, et al., 2014 |
| The Importance of Stigma and Discrimination Among People with Mental Illness | McGonagle, et al., 2014 |
| The Relationship between Stigma and Help-Seeking in Jordanian University Students | Hashimoto, et al., 2016 |
| The Psychometric Properties of a Japanese Version of the Stigma Scale for Chronic Illness | Motoguchi, et al., 2016 |
| The Effect of Internalized Stigma on Quality of Life Domains in Participants with Type 2 Diabetes | Takada, et al., 2016 |
| The Stigma Scale for Chronic Illness: A Theoretically Based Model of the Individual Worker | Farrell, et al., 2014 |
| The Self-Stigma Scale in People with Type 2 Diabetes | Molina, et al., 2014 |
| The Quality of Life of People with Type 2 Diabetes | McGonagle, et al., 2014 |
| The Impact of Stigma on the Quality of Life of People with Type 2 Diabetes | Raymond, et al., 2014 |
| The Application of the Stigma Concept in Nursing Researches | Ahmad, et al., 2019 |
Individuals with cancer are stigmatized in several countries (Fujisawa and Hagiwara, 2015). Stigma is associated with a variety of social consequences; clinical outcomes; unwillingness to look for treatment; and augmented feelings of suffering from cancer (Knapp et al., 2014). Although cancer stigma research is still somewhat new and has grown quickly; still there is a lack of agreement between researchers on how to conceptualize cancer stigma, (Fujisawa and Hagiwara, 2015).

Many researcher found that there were inconsistent theoretical frameworks and the subsequent disparities in assessment approaches that make difficult to reach powerful conclusions from them (Chambers et al., 2012; Knapp et al., 2014). Knapp et al., (2014) suggested for understanding cancer stigma and differentiating it from other social stigmas to use a modified version of contributors to the stigma-induced identity-threat model created by Major and O’Brien (2005). Whereas this model offers an admirable foundation for understanding the relationship between identity threat and stigma, not all types of cancer can be understood using it (Knapp et al., 2014).

Pragmatical

The third premise in the principle-based concept analysis method refers to the applicability and usefulness of the stigma concept and how it is operationalized (Penrod and Hupcey, 2005). It is difficult to reach a complete and clear definition for clinical concepts because it is dynamic and changeable over time; influenced by history, clinical care; and the occurrence of innovation in health conditions and diseases (Florom-Smith and Santis, 2012).

Stigma has several inconstant definitions and applications. Unrecognized stigma is an obstacle for understanding the patient actions (Pinto-Foltz & Logsdon, 2008).

There are many operational definitions for stigma in nursing literature (Florom-Smith and Santis, 2012). Examples of well-established and most widely used instruments in nursing research include “Internalized Stigma in Mental Illness (ISMI)” instrument, which was developed by Ritsher et al., (2003). This instrument is a 29-item rated on a four-point Likert scale. The internalized stigma was defined as “inner subjective experience and its psychological effects, including alienation, stereotype endorsement, perceived discrimination, social withdrawal, and stigma resistance” p32. Another tool that commonly used is The Self-Stigma of Mental Illness Scale (SSMIS), which was developed by Corrigan et al., (2006). This scale has four subscales (stereotype awareness, stereotype agreement, stereotype self-concurrence, and self-esteem decrement) with 40 items; each item rated on a nine-point agreement scale. The Japanese version of the Self-Stigma Scale (SSS-J) is another example that contains 39 items allows responses in 4-point anchored Likert scale: strongly disagree, disagree, agree, and strongly agree. The responses are afforded a score of 0, 1, 2, and 3, respectively. The total scores have a range of 0 to 117; a higher score signifies a higher level of self-stigma (Kato et al., 2014).

Despite the growing body of knowledge about stigma associated with cancer screening, diagnosis, management, and consequences, awareness about measurement of cancer-related stigma is little (Edelen et al, 2014). There are different tools that were established for the purpose of assessment and measurement of cancer-related stigma (Marlow and Wardle, 2014). Edelen and colleagues (2014) developed a Global Cancer Stigma Index (CSI) to measure cancer-related stigma, which anticipated to help health policy makers and program developers to identify gaps of education that change and correct population’ misconceptions about cancer that is contributing to the development of stigma. The CSI is composed of 12-items in which higher score is correlated with higher cancer stigma, and subsequent lower treatment-seeking rates, less psychological well-being, and greater social isolation among cancer patients.

The Cataldo Lung Cancer Stigma Scale (CLCSS) is an instrument measures cancer-related stigma among patients with lung cancer, which was developed and validated by Cataldo et al., (2011). CLCSS is a valid and reliable 31-items instrument that is composed of four subscales: stigma and shame, social isolation, discrimination, and smoking. Marlow and Wardle (2014) rose up the awareness of cancer-related stigma for non-patient population. They developed a validated Cancer Stigma Scale (CASS) for the use in general population. The validated CASS consists of 25-items distributed over six subscales: awkwardness, severity, avoidance, policy opposition, personal responsibility and financial discrimination. Validated CASS is intended to identify if proper interventions are designed to minimize cancer-related stigma among non-patient population in different communities. Examples of applications and instruments used in nursing research are presented in Table 2.

Linguistical

The fourth premise refers to the evaluation of the concept, whether it is the appropriately and consistently used in the context (Penrod and Hupcey, 2005). Stigma is a complex, multi-faceted, construct (Webb et al., 2016). Without knowing which concept is related to stigma, it is problematic at this point to know how concepts affect or influence stigma (Nyblade, 2017). Stigma is a social construct that recognizes a person by virtue of a physical or social trait, resulting in negative social reactions such as avoidance and discrimination (Hassan and Walsheh, 2011). Furthermore, stigma is a universal and multidimensional concept that experience in various stages of life in all cultures (Pinto-Foltz and Logsdon, 2008). Accordingly, stigma as a concept vary from context to context, and it is viewed as negative issue, which have different dimensions: interpersonal; intrapersonal; and structural (Butt, 2008).

Despite stigma’s relevance to nursing, few literature revealed the meaning of stigma in nursing. Nurses commonly search for helping psychiatrist and psychologist in defining stigma (Pinto-Foltz and Logsdon, 2008). Although, the role of culture toward a stigma is clear in the literature, few studies discussed stigma from cultural
Increased awareness and acceptance of mental illness may represent a cultural shift toward illness. There is a relationship between stigma and loss of social identity. Increased awareness and acceptance of mental illness may lead to reductions in stigma.

Discussion

Stigma concept was evaluated for its maturity level based on Morse et al.’s (1996) principles. Studies showed that stigma plays a greater role among underserved populations than general populations. Most of the studies were consistent in which stigma is a complex and had multi-dimensions. Effective nursing care requires additional awareness, and understanding of stigma concept and abilities of nurses to manage and deal with stigmatizing people in order to improve the health care process.

Literature demonstrated that different types of cancer have different levels of stigma, which could be attributed to the type of cancer, possibility of treatment, and the psychological tolerance of the individual (Else-Quest and Jackson, 2014). Stigma appears to be associated more with patients who have lung cancer, especially among smokers, than other types of cancer (Chambers et al., 2012). People ranked lung cancer as more severe than other types of cancer such as breast, colorectal, cervical, and skin cancer (Knapp et al., 2014).

Stigma is a complex phenomenon that can be found in many health care environments and affects the caring process for both the individuals and the community (Ahmad, 2015; Nyblade, 2017). Although there is a large body of literature that addresses the concept of stigma, there is no consistency in the definitions, dimensions and operationalization’s of stigma. Literature suggests that stigma varies across time and among cultures (Brinkley-Rubinstein, 2015). However, there is still a lack of clear theory to explain how it varies across different types of a disease. With the increase in public awareness about the etiology of cancer and its consequences, stigma becomes a more central issue for some types of cancers.

Understanding stigma concept plays an important role in delaying or preventing patients’ treatment (Halter, 2002). Stigma has a negative influence on people’s lives, creating social distance, which interferes with their interactions with people in the society. There is a relationship between stigma and loss of social identity. Increased awareness and acceptance of mental illness may lead to reductions in stigma.

There are numerous studies dealing with stigma, however, several gaps remain, particularly with measuring and defining stigma (Omori et al., 2014; Florom-Smith and Santis, 2012). Therefore, further concept development and clarification are needed. Nurses and other health care professionals should work on the definition of stigma concept and reach global consistency regarding the conceptualization and operationalization of stigma and keep it related to cultural context (Dalky, 2012).

In conclusion stigma as a concept remains uncertain; the meaning of stigma is varied among different culture. How stigma is defined can help nurses in many aspects. Conducting research studies to understand the stigma concept helps nurses to develop realistic interventions that increase public awareness of the stigmatization phenomenon. Furthermore, to positively benefits stigmatized population, clarifying the concept of stigma among health care providers helps to support patients and families by educating them and increasing their acceptance toward illness. There is a relationship between stigma and loss of social identity. Increased awareness and acceptance of illness may reduce the level of stigma among patients and their family.

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