

# The concept analysis of stigma towards chronic illness patient

## Abstract

**Introduction:** Stigma among different diseased patient is evident and most common in resource-limited countries, like Ethiopia. A patient with chronic illness faces a different type of stigma. Having a chronic illness or disease and being different from the community subjects a person to a possible stigmatization by those who do not have the illness.

**Objective:** To describe the concept of stigma among chronic illness patients.

**Methods:** Walker and Avant's method of concept analysis.

**Results:** Stigma in chronic illness has antecedents which include a chronic illness, non-adherence to health care provider recommendations, lifestyle risky for chronic illness, and perceptual and social inequality. Type of chronic illness, comorbidity, age, Sex, economic status and complication related to the disease, misunderstanding, labelling, and separation or withdrawal from family/society can be the attributes. The consequences of stigma can be seen at home, in the work environment, and in the community. It defers care-seeking behavior and treatment, drug resistance, or increases treatment costs for treatable health consequences.

**Conclusion & recommendation:** As stated in the different scholars, today the stigma shown among chronic illness patient is increasing from time to time. To know the concept behind stigma in chronic illness patients; developing a validated tool, assessing the situation and intervention based on the finding will improve the quality of life of the patient with different chronic diseases. Also, to the government and concerned bodies, it will show the way to minimize stigma.

**Keywords:** concept analysis, nursing, stigma, chronic illness patient

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## Introduction

The concept of stigma was primarily introduced as a relationship between an attribute and a stereotype and lead to negative attributes, weaknesses or disadvantages in the quality of life of the patient.<sup>1</sup> Chronic diseases, such as acquired immune deficiency syndrome (AIDS), diabetes, cardiovascular disease, and epilepsy create a socio-economic burden to society as well as the patient. The magnitude of stigma in these conditions is, however, quite different.<sup>2</sup>

Stigma affects the delivery of health care and may interfere with the patients to attendance of necessary services. Despite its damage, stigmatization is not well-understood and often not recognized, even by those directly involved.<sup>3</sup>

Different scholars tried to assess stigma levels in different ways.<sup>4,5</sup> But still, we cannot get a clear measurement tool for the level of the stigma of a chronic illness patient in resource-limited settings. Therefore, assessing the stigma concept in chronic illness patients will have an important impact to improve the quality of life and decrease stigmatization level. And it will also benefit to increase the adherence of patients, identify possible positive outcomes, and decrease health care cost as a whole.

## Discussion

### Stigma (in the literature)

The term stigma refers to unwanted signs designed to expose something unusual and bad about the moral status of the signifier/patient.<sup>1</sup> "Stigma is typically a social process, experienced or

anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group. This judgment is based on an enduring feature of identity conferred by a health problem or health-related condition, and the judgment is in some essential way medically unwarranted."<sup>6,7</sup> In the case of chronic illness stigma, the mark or attribute is the diagnosis of chronic disease. With this diagnosis, a person has transitioned from 'normal' to 'limited function'.<sup>1</sup>

A patient with chronic illness may face a different level of stigma and create a barrier between the sick and the rest of society. Stigma prevents them from acting on their instinctive desire to seek curative treatment that will enable them to re-enter their everyday social activity.<sup>8</sup> Many diseases, for example, TB, HIV/ acquired immune deficiency syndrome (AIDS), leprosy and chronic disease, like mental disorder enormously affect the patient, are connected with stigma.<sup>9</sup>

The negative use of the term stigma for showing a mark of shame or degradation is thought to have appeared in the late 16th and early 17th centuries. Prior to that, stigma was more broadly used to indicate a tattoo or mark that might have been used for attraction or religious purposes, or for utilitarian reasons, such as identification or mark on slaves or criminals so that they could be identified if they ran away and to indicate their inferior social position.<sup>10</sup> To better understand the sources of stigma in the world, a closer look at the history of the concept is necessary. The presence of disease-causing stigma arguably antedates the Pre-Modern era. Nonetheless, perhaps the most infamous historical figure to bear the blight of stigma was Mary Mallon (a.k.a. Typhoid Mary). During the early 1900s, Mary

Mallon was shunned and captured by local authorities for her role in spreading typhoid. She represented a healthy carrier of typhoid and unknowingly spread the disease to people for whom she prepared meals. She underwent a great deal of trauma and hardship as a result of her unfavorable condition, and her permanent label (i.e., Typhoid Mary) signifies the stigma she endured.<sup>11</sup> During the era of 'Typhoid Mary' and prior to the social activism of the 1960s and 1970s, the Tuskegee Syphilis Study that spanned four decades was symbolic of the injustice and stigma directed toward African American males during the middle part of the 20th century.<sup>12</sup>

Essentially, the term, "disease" induces a sense of stigma. Stigma occurs in the presence of diseases, such as gonorrhoea,<sup>13</sup> herpes, human papillomavirus (HPV),<sup>14</sup> hepatitis,<sup>15,16</sup> Alzheimer's disease,<sup>17</sup> severe acute respiratory syndrome (SARS),<sup>18</sup> autism,<sup>19</sup> psoriasis,<sup>20</sup> and attention deficit hyperactivity disorder.<sup>21</sup> In Ethiopia, Stigma has resulted in a lack of treatment and adherence to therapies and shows marked problems in different professions (including nursing) and in rural communities.<sup>9,22</sup>

Although stigma has negative outcomes for the patient, it also sometimes has a positive outcome for leaders to follow workers who are not adhering to the rule. And some patients may use their disease status to get enough medical benefit due to their stigma<sup>1</sup> and to control the spread of different infectious disease agents like the Ebola virus.

### A model case

A 50-year old male with a known history of chronic illness diabetes for the past one year comes to the chronic illness clinic at the University of Gondar Comprehensive Specialized Hospital for his monthly follow up. Recently he was not attending the regular schedule and taking medication as ordered. The reason he mentioned did not understand the disease condition and fear (shame) to tell his family. He observed one close family which had the same disease and saw he was not getting married due to the disease (misunderstanding). Also, he was afraid that he might not cope with the disease and work like others (labelling) due to his feeling of tiredness and excessive hunger.

### Related case

A 43-year old female patient with a new diagnosis of type II Diabetes and hypertension (stage III) complained why her health was not getting better after she took the prescribed medication (misunderstanding) and has had she notices two episodes of fainting in the last two months. Due to her medical condition, she decided to separate from her husband. She thought that she would be dead in the near future (failed labelling).

### Borderline case

Madam Almaz a newly diagnosed hypertensive patient came to the clinic for her first appointment. She complained had fainting, dizziness, and difficulty to stand. And had some discomfort with feeding due to the new drug. And she thought that her weight increased and faced mental problem due to the hypertension drug (misunderstanding). She reported that because of fear of taking the hypertensive drug for lifelong, she denied the first diagnosis. She was well supported by family members and had good counseling during the first diagnosis, but she was highly disturbed at that time.

### Contrary case

A young man 19 years old comes to a clinic for complaining of loss of consciousness, convulsion, and high-grade headache. Before

two weeks he was diagnosed with convulsive seizure (epileptic). He said he fell down from a height two years ago and lost consciousness at that moment. At the moment, his family was supporting him, but they were afraid to tell his friends about the disease condition due to fear of stigma (failed labeling). He started the medication during the first visit, but he said he was not taking the prescribed medication as ordered (failed misunderstanding). At the moment, he agreed to take the prescribed drug and not to tell any friend until he controlled the seizure and not to be away from family in order to avoid further damage due to seizure (absence of internalization, status loss, and shame).

### Antecedents of stigma towards chronic illness patients

The antecedents of stigma among chronic illness patients include having a chronic illness, non-adherence to health care provider recommendations, lifestyle risky for chronic illness, the perception of inequality and social inequality. Also a misperception of the social condition of the individual or group by labeling them as they are at disadvantages.<sup>23</sup>

### Attributes of stigma towards chronic illness patients

Walker & Avant defined attributes as characteristics that appear in a concept repeatedly and help researchers distinguish the occurrence of a specific phenomenon from a similar one.<sup>24</sup> The attributes of stigma are more consistent but not always cited, leading to literature in which stigma is named as a factor and to a greater or lesser extent explored though not concisely defined. The different attributes may lead to stigma. The most common are types of chronic illness, comorbidity, age and sex of the patient, economic status, and complications related to the disease. Also, misunderstanding, labeling, and separation or withdrawal from family/society can be the attributes.<sup>23</sup>

### Consequences

In contrast to antecedents, Walker and Avant have defined consequences as 'those events or incidents that occur as a result of the occurrence of the concept'.<sup>24</sup> The effect of stigma can be seen at home, in the work environment, and in the community. It defers care-seeking behavior and treatment, results in drug resistance or increases treatment costs for treatable health issues.<sup>25</sup> Due to stigma the patient may lose follow up, hide status, get depressed, assume social withdrawal, has decreased quality of life, and ends up in increased morbidity and mortality, increasing the cost of service for chronic illness due to resistance for different drugs. Patients with stigma have been reported to have poor social interactions and avoid medical care and continuation of treatment.<sup>26</sup>

People diagnosed with chronic illnesses report experiencing social rejection,<sup>27</sup> workplace termination<sup>28</sup> and poor healthcare<sup>29</sup> due to their chronic illnesses.

### Related concepts

Different concepts related to self-stigma include enacting and anticipating stigma, discrimination, prejudice, and stereotyping directed at them from others and/or internalized stigma (i.e., endorsing negative stereotypes about people living with chronic illnesses and applying them to the self).<sup>4,30</sup>

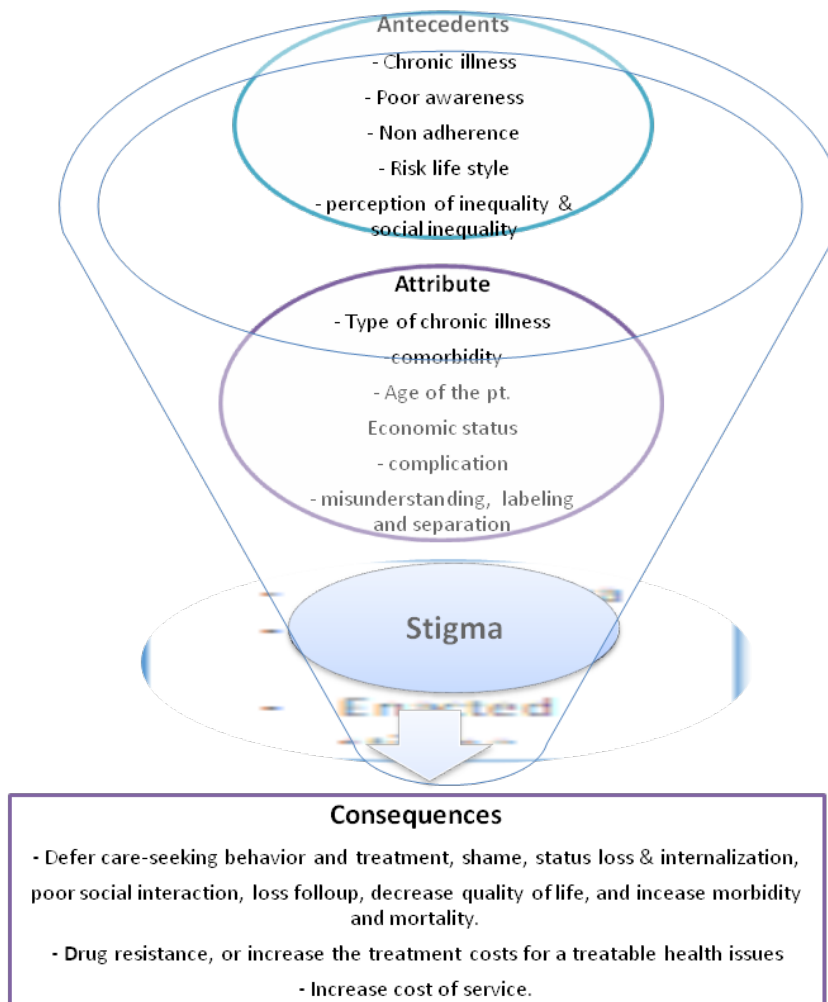
### Empirical referents

According to Walker and Avant's, empirical referents are "classes or categories of actual phenomena that by their existence or presence

demonstrate the occurrence of the concept itself” (p. 73).<sup>24</sup> To assess the concept of stigma different scholars tried to use valid and reliable tools in different settings and situations. But towards chronic illness,

we can’t get a clear-cut direction in which way we can get the status in the current situation.

**Concept map (Figure I)**



**Figure I** Concept analysis of stigma towards chronic illness patient conceptual map developed from different literature.

**Review tools used to measure stigma**

I randomly selected some of the tools used for different chronic illness in the following paragraphs. The first one was Chronic Illness Anticipated Stigma Scale (CIASS) with a 12-item scale with three subscales differentiating among sources of anticipated stigma incorporating members of family and friends, healthcare workers, and work colleagues. Their results enhance the reliability, validity, and generalizability of the selected samples of chronic illness patients.<sup>4</sup>

The second one was the Stigma Scale for Chronic Illnesses the 8-item version (SSCI-8); it was developed by Dr. Yamile Molina and her research group. Even though the impact of stigma has been highlighted for an epileptic population, the experiences of people living with other neurological conditions have been less studied.<sup>31</sup>

Thirdly, a measurement for the Stigma of mental illness was also developed by Michael King and his colleague. They used qualitative data from interviews with mental health service users to develop a pilot scale with 42 items. In discrimination and stigma scale, there are four parts to this interview. Each part asks about how you have been treated or what you have done in different situations.<sup>32</sup>

Internalized Stigma of Mental Illness Inventory-a 9-item Version (ISMI-9) tool was also developed by Hammer, J. H., & Toland, M. D. The ISMI-9 contains 9 items Likert type question which produce a total score of 9. Reverse-code items 2 and 9 before calculating the total score. The interpretation of the score for internalized stigma of mental illness inventory was categorized either by a 4-category method or by dichotomizing the result.<sup>33</sup>

## Conclusion

Currently, the prevalence of chronic illness (diabetes, cardiovascular disease, and mental illness) is increasing from day to day. Stigma toward a chronic illness patient may be seen evidently in different conditions. Developing a validated tool, assessing the situation and intervention based on the finding will improve the quality of life of the patient with different chronic diseases. Also, to the government and concerned bodies, it will show the way to minimize stigma.

## Limitations

Even if, this concept analysis paper is tried to show the stigma concept; the tools who selected was random. Due to that, it may create a bias for the reader.

## Declaration

### Availability of data and material

The raw data would not be provided for the reason of protecting patients' confidentiality. But, the main finding of the data is available in the main document.

### Authors' contributions

MHS wrote the concept paper, participated in data collection, analyzed the data and drafted the concept paper. TL approved the concept paper; participated in concept analysis and revised subsequent drafts of the paper.

### Acknowledgments

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### Competing interests

Authors declare that there are no competing interests.

### Consent to publish

Not applicable

### Ethics approval and consent to participate

This concept paper was part of Nursing PhD program in the School of Nursing University of Gondar College of Medicine and Health Sciences. Permission was obtained from the school ethical committee. Each patient was informed about the purpose, method, expected benefit, and risk of the study. Patients were also informed about their full right not to disclose their information at any time. Written informed consent was obtained from study participants' and anonymity was employed by changing their name and removing ID to maintain confidentiality.

### Funding

There is no funding for this research

## Patient consent form

Dear hospitalized patients (participants)

My name is \_\_\_\_\_. I am working as researcher and Ph.D. in nursing first-year student at the University of Gondar, College of Medicine and Health Sciences, school of nursing. The aim of this study is to describe the concept of stigma among chronic illness among hospitalized patients in University of Gondar Comprehensive referral and specialized Hospital, Northeast Ethiopia.

This concept analysis result which may help policymakers, responsible persons in the health institution, and significant others to take actions based on the findings. The study will be conducted in reviewing your history sheet on the chart. The information we got from the chart will be completely confidential and purposefully changed the name and age. It is your full right to refuse. However, your willingness will help us in a better understanding of stigma among patient with chronic illness, so; we are requesting you to give your honest volunteer and keep participation.

### Risk and Benefit

On this research, there is no risk and/or direct benefit for a patient. But in long term, it will clearly identify negative and positive factors towards the stigma

### Incentives/Payments for Participating

You will not be provided any incentives or payment to take part in this research.

### Confidentiality

The information collected for this concept analysis will be kept confidential and information about you that will be collected by this study will be stored in a file, without your name, but a code number assigned to it and purposefully changed the name and age. And it will not be revealed to anyone except the primary researcher.

### Right to Refusal

You have full right to refuse from permitting the information on your chart and this will not affect you from getting any kind of health service in the hospital. You have also the full right to leave from this study at any time you wish, without losing any of your rights.

### Person to contact

This concept analysis will be reviewed and approved by the responsible person. If you want to know more information you can contact through the address below. If you have any question you can contact at any time you want.

1. Mr. Mohamed Hassen University of Gondar, College of Medicine and Health Science, School of Nursing, Ph.D. in nursing first-year student and Lecturer

Mobile: 0918785735

Would you willing to participate in this study?

1. Yes ----- sign-----
2. No

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