

Leprostigma : A Concept Analysis

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Leprostigma negatively impacts on leprosy afflicted persons (LAPs). Understanding the concept of Leprostigma is very important in providing optimal nursing care for LAPs. However, this concept remains obscure in the literature and has been defined differently in various studies. The use of different terms for this concept has made its use more complicated in practice. This concept analysis attempts to analyze the leprostigma concept to clarify, reduce ambiguities, semantic integration, and increase stability in applying the concept. The relevant literature was reviewed using Walker and Avant's framework, and the attributes of Leprostigma were determined. Leprostigma manifests in three main faces that their attributes determine the boundaries of the concept. Enacted-Leprostigma defines as externally humiliating behaviors and discrimination experienced and perceived by LAPs. Felt-Leprostigma is the anticipation, expectance, prejudice, or fear of LAPs of label attachment and discrimination by others. Self-leprostigma defines as an unfavorable personal experience of self-discredited, feeling of inferiority, and self-loathing. Leprostigma developed from a primitive concept with emphasis on LAPs attributes to the concept with a complex social structure. It occurs in a broad spectrum of unfair and negative consequences through a dynamic process. This concept analysis can improve the implementation of more extended studies and the development of research tools as well as practice. It is observed that different kinds of Leprostigma have overlapping values and affect each other. As a result of analysis presented in this study, it is recommended that the term "Leprostigma" be used instead of various leprosy-related stigma terms.

Keywords : Concept Analysis, Leprostigma, Leprosy, Stigma, Walker and Avant.

Introduction

Leprosy is one of the age-oldest diseases which had been described in the ancient literature of India and China (Grön 1973, Trautman 1984, Bennett et al 2008). In scientific writings, perhaps

the oldest narrative belongs to Avicenna, which described leprosy and patients characteristics (Zamparoni 2017). Leprosy remains a significant public health problem in several parts of the world. In 2017, WHO reports that there were

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211,009 new globally leprosy registered cases (according to official figures taken from 159 countries in from the 6 WHO regions). Therefore, the prevalence rate of leprosy was reported 0.3/10,000 in 2017 (WHO 2018, WHO 2019). Leprosy afflicted persons (LAPs) suffer from neuropathic lesions, and it causes limb deformity and osteomyelitis, which sometimes required amputation. Besides, dryness and corneal ulcer may lead to decreased vision or blindness. Also, Cataract is commonly found in leprosy cases (van Brakel et al 2012). However, despite the success of multidrug therapy (MDT) as a confirmed and definitive leprosy treatment, Leprostigma (stigma related to being a LAP) persists in many countries (Sermrittirong & van Brakel 2014).

Leprosy, one of the most known stigmatizing diseases and people afflicted by it have been ostracized by their communities (Kumar et al 2019, WHO 2019). Historically, leprosy was understood to be a hereditary, incurable, and curse from God (Lancet 2019), and leprosy was a means of separation and isolation (Zamparoni 2017, Lancet 2019, Singh et al 2019). Leprostigma poses many cultural and social challenges for LAPs and has a profound effect on the lives of patients and their families (Chaidee 2006). It often imposes a heavier burden than those imposed physical symptoms of the disease (Weiss et al 2006, Adhikari et al 2014a, Kaehler et al 2015, Dadun et al 2019). LAPs face severe reactions from the community and discarded from society due to public over-fears of the disease (Sermrittirong & van Brakel 2014, Dwivedi 2018).

Leprostigma is likely to be one of the biggest obstacles to medical care and can lead to LAPs concealing their illness or forcing them to leave their homes. Finally, they will come to the medical centers when advanced physical impairments, psychological problems, and painful experiences have already occurred for them. This issue has

adverse consequences in leprosy control (Weiss 2008, White 2011, Franco Paredes et al 2016). One of the main pillars of WHO Global Leprosy Strategy 2016–2020 is based on stops discrimination and promote inclusion (WHO 2016). Heijnders pointed out that "A stereotypical view about leprosy is still dominant" (Heijnders 2004).

Stigma is an old complex concept that has a broad application in the studies covered under various disciplines. Some studies have focused on the stigma concept in general, and some research efforts carried out to assess the stigmas types, causes, and effects on LAPs. Nevertheless, the Leprostigma concept's boundaries and clarity have hidden behind the body of growing research on leprosy. Some terms, such as Discrimination, Prejudice, and Stigma, are often used interchangeably, leading to ambiguity. Awofeso (2005) states that "The term discrimination embraces most, but not all, facets of the concept and impact of leprosy stigma". Different authors define Leprostigma differently, and the concept used vaguely in practice. Besides, in various literature, different terms such as Stigma toward Leprosy, Stigma related to Leprosy, Stigma of Leprosy, Stigma in Leprosy, Leprosy Stigma have been used for this concept, which has reduced semantic integration of the concept.

Achieving success in the LAPs treatment and enhancement of the quality of life depends on reducing the Leprostigma through shifting the views of society to these patients (Rao 2010, Van't Noordende et al 2019). The understanding of the Leprostigma concept is the basis of practical planning to destigmatize and the clinical care of LAPs and providing social support as well as eradication of leprosy. Accordingly, the researcher chose this complex concept for analysis. Because there is limited knowledge about the concept of Leprostigma in the

literature, this study aims to analyze Leprostigma to clarify, reduce ambiguities, and increase semantic integration and stability in the application of the concept.

Materials and Methods

Study design : A concept analysis

The study used the systematic approach of Walker and Avant to conduct a concept analysis of Leprostigma. Concept analysis is a valuable methodology, which enables the researcher to define concepts, to clarify the features and their relationships with other concepts, and to distinguish it from similar and different concepts. This process is an exact methodology that is used to detect hidden semantic elements in the concept (Walker & Avant 2005). Concept analysis has been widely supported as one of the essential approaches to exploring the development of nursing knowledge and one of the processes of Philosophical analysis. When analyzing the concept, the principles and criteria governing the use of the concept are discussed (Tadd & Chadwick 1989, McKenna 2002). The Walker and Avant approach is a simplified form of the Wilson classic approach and provide clarity from existing literature. This logical positivist approach can make it more transparent by simplifying a complex concept, such as Leprostigma, as well as its applicable situations in the clinical setting (Fig. 1) (Walker & Avant 2005, Nuopponen 2010).

Data collection

A literature review was conducted at the beginning of the concept analysis to collect data. The review was done without time limitation in three online databases main including PubMed, ISI, and Scopus using "Leprosy," "Social Stigma," and "Stigma" keywords. All 790 selected articles were exported to the End Note library. Duplicate records and books were removed from the

EndNote library. Subsequently, the non-relevant articles were removed from the End Note library by screening articles' titles and abstracts. Articles that were not accessible or were in a language other than English were excluded. The full text of the rest of the articles was scanned, and 52 articles that discuss Leprostigma were retrieved. Fig. 2 shows the flowchart of the main reporting points of this literature review.

Results

Literature expresses different definitions of the stigma concept and its conceptual framework (Table 1).

Determine the Defining Attributes

Leprostigma is a complicated Concept. Since defining attributes of Leprostigma plays a crucial role in differentiating the analyzed concept from similar concepts, these attributes were defined at the first step of Walker and Avant's approach (Walker & Avant 2005). According to Walker and Avant's method, to determine the defining attributes of Leprostigma, were viewed the relevant literature, to find characteristics that repeatedly appear. The narrative review's findings determine the conceptual scope and better delineate the boundaries of the Leprostigma concept.

- Externally humiliating behaviors and discrimination expressed by the public (individual or group), from very rough (Ostracism) to subtler forms (Gaze), experienced and perceived by the LAPs (Enacted/experienced stigma or discrimination) (Scambler 1998, Heijnders 2004, van Brakel 2006, van Brakel et al 2011, Adhikari et al 2014b).
- LAPs anticipation, expectance, prejudgment or fear of LAP label attachment, prejudices, and discrimination by others because of awareness of public stereotypes in the case of "being a

LAP" (perceived/anticipated or felt stigma) (Hyland 1993, Scambler 1998, Van Brakel 2006, van Brakel et al 2011, Adhikari et al 2014b).

- An unfavorable personal experience of self-

discredited, feeling of inferiority and self-loathing, because of the acceptance and internalized of public stereotypes/prejudices in the case of being a LAP (self or internalized stigma) (Scambler 1998, Heijnders 2004, van

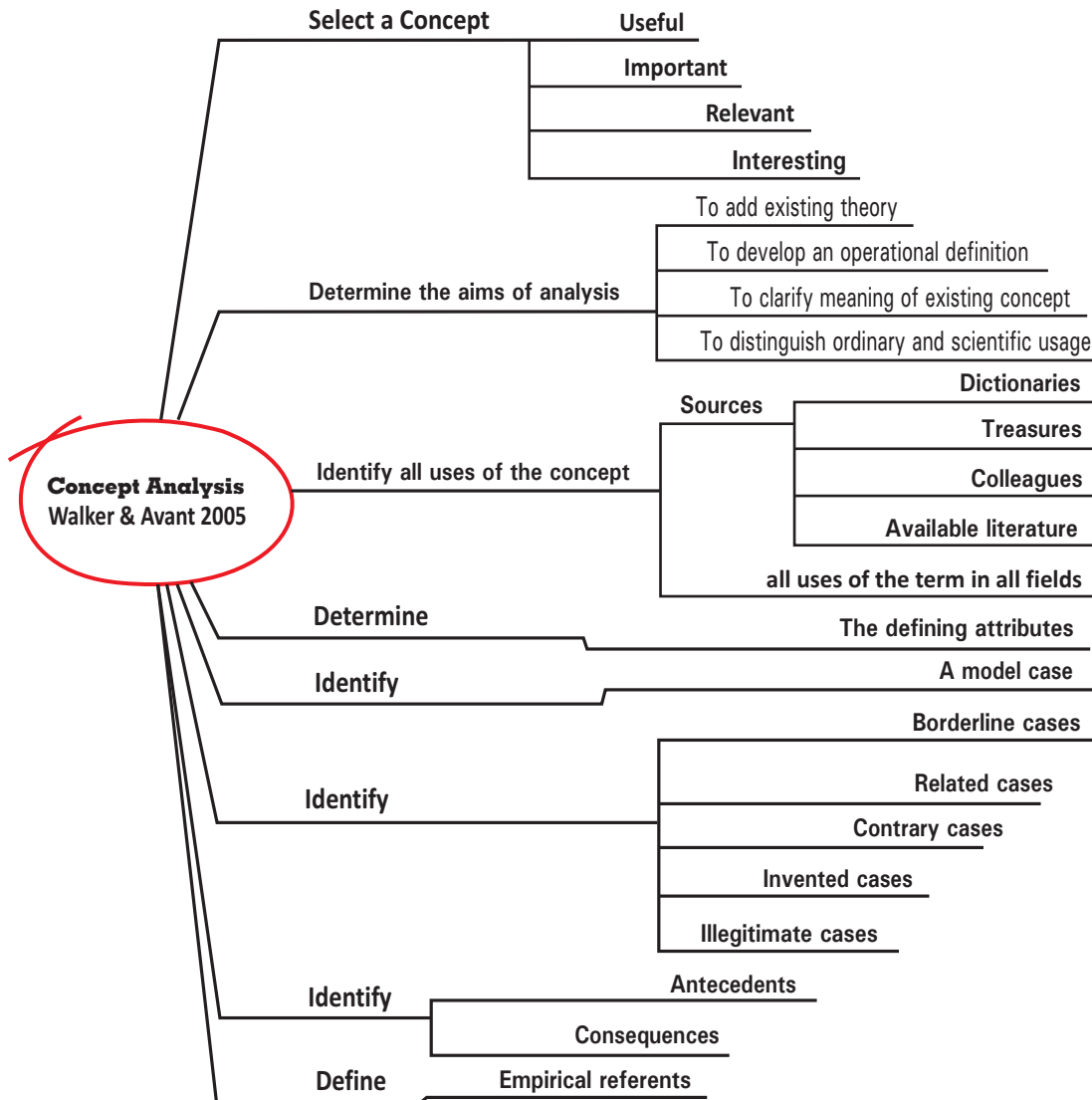


Fig.1 : Walker and Avant's concept analysis model

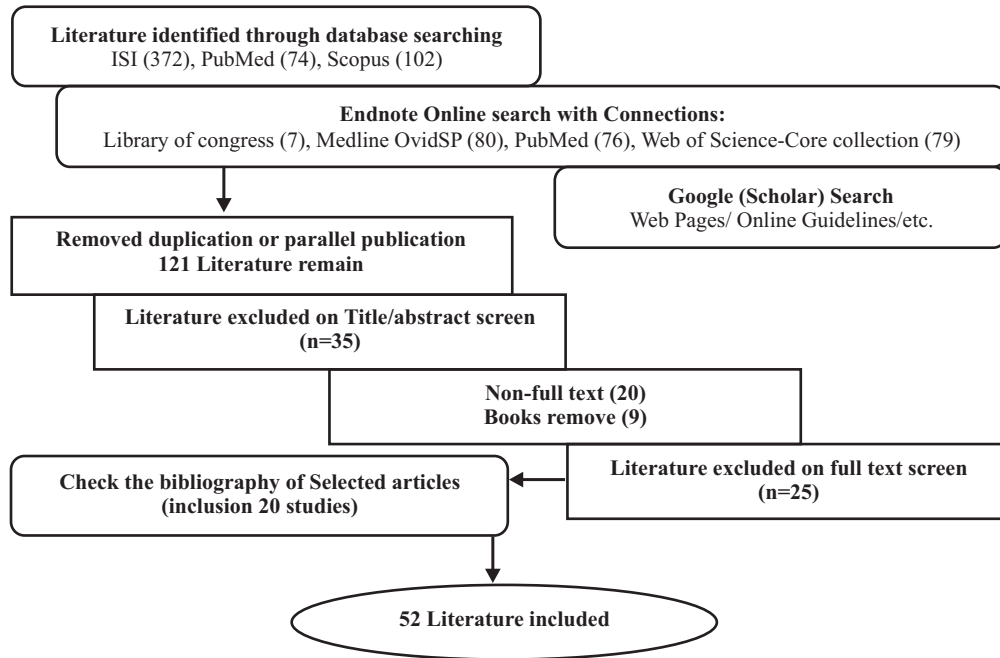


Fig. 2 : Flow diagram of data collection and flow of article inclusion and exclusion from review

Table 1. Definitions of "Stigma"

Author	Definition
Goffman 1963	The situation of the individual who is disqualified from full social acceptance
Jones et al.1984 *	A mark or attribute that links a person to undesirable characteristics or stereotypes.
Stafford & Scott1986	A characteristic of a person that is contrary to the norm of a social group or unit.
Crocker et al 1998	Stigmatized individuals possess or are believed to possess some attributes or characteristics that convey a social identity that is devalued in a particular social context.
Link et al 2001	A dynamic process that is linked to competition for power and tied into existing social mechanisms of exclusion and dominance.
Parker et al 2003	A social process that involves identifying and using the difference between groups of people to create and legitimize social hierarchies and inequalities.

Castro et al 2005 *	A result of structural violence perpetrated by the larger social forces that are rooted in historical and economic processes.
Major et al 2005 *	Social stigma—of being labeled, negatively stereotyped, excluded, discriminated against, and low in social status and power.
Jacoby et al. *	A label associating a person to a set of unwanted characteristics that form a stereotype.
Gary 2005	A collection of negative attitudes, beliefs, thoughts, and behaviors that influence the individual, or the general public, to fear, reject, avoid, be prejudiced, and discriminate against people
Weiss et al 2006	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
van Brakel 2006	Stigma is a global phenomenon with a severe impact on individuals and their families and the effectiveness of public health programs.
Yang et al. 2007	Stigma can be used to enforce social imperatives upon stigmatized individuals, whose trait deviance is perceived as a breach of those social imperatives.
Livingston et al 2010**	A subjective process, embedded within a sociocultural context, which may be characterized by negative feelings (about self), maladaptive behavior, identity transformation, or stereotype endorsement resulting from an individual's experiences, perceptions, or anticipation of negative social reaction based on their health condition.
Sermittirong & van Brakel 2014	Stigma is a complex phenomenon that has multiple causes, often linked to the cultural context in which it occurs.
Pescosolido et al 2015	A deeply discrediting attribute,"mark of shame,"; "mark of oppression,"; devalued social identity.

* Quoted from Sermittirong & van Brakel 2014

** Quoted from van Brakel et al 2012

Brakel 2006, van Brakel et al 2011, Adhikari et al 2014b).

- Affects emotions, thoughts, behavior, relationships, socioeconomic status, family members of LAPs, persisting after the disease is cured (Augustine et al 2011, Lusli et al 2015).

Identify a Model Case

At this step of the analysis, to clarify the concept and its attributes, use a model case, which represents a real-life example of the use of the concept that includes all the critical attributes of the concept (Walker & Avant 2005). The following

has been created using statements from patients interviews that have been described in the literature:

"A few months ago, I was finally cured from leprosy, but nobody wants me to work in their house; people avoid me and ridicule me because of my crooked hand... expressly avoid us and they continually label us as patients with a contagious disease.... meeting people, for me, means being insulted" (Lusli et al 2015). (model case of Enacted Leprostigma)

"We are shy and have doubts about participating in daily life activities. We prefer to remain silent about our negative feelings, not because of us but because the community puts a label on us"(Peters et al 2013). (model case of Felt-Leprostigma)

"It is impossible having social interaction with others. I am ill, I must be cured, get my hand back first, then I can go out. I believe people do not want to be friends with a sick person with a crawling hand like me" (Lusli et al 2015)". (model case of Self-Leprostigma)

Additional Cases

To assist the researcher in judging the critical attributes, they propose to examine cases that are not the same concept and are similar to or opposed to the concept. Additional cases are intended to provide examples of what the concept is not intended to be and to define more clearly and assurance of what the concept is intended for. Not all of these additional cases are necessarily included in individual concept studies in nursing science (Walker & Avant 2005).

Borderline Case

The borderline case contains some, but not all, of the concept's defining attributes. This example is very similar to the model case, but also distinct from the case. Their inconsistency helps us to see why the model case is so accurate (Walker & Avant 2005).

".... I got married when I had leprosy deformities; when he proposed to marry me I asked him that there are very many young girls who are normal and why have you come for somebody without fingers and toes, anyway it is only his death which separated us" (Raphael et al 2017).

Related Case

In the related case, some defining attributes are present, but not all.

"We are ill. Going to the community health services, getting and taking our medicine regularly, meeting the health officers if we are in pain, and asking for medical treatment. That is enough. Just to do these actions is enough" (Lusli et al 2015).

Contrary Case

The contrary case does not contain any of the defining attributes and illustrates what the concept is not.

"My leprosy was diagnosed 25 years ago when I was 14. I did not take my multidrug treatment correctly initially partly because I was following religious fasts. After explanations from the doctors, I understood the need for taking the drugs regularly. Leprosy is not like other diseases. It damages a person so slowly. If you get the treatment you can change the course of the disease. At least it does not kill you! The fact that I can do any job makes me feel good. I have beautiful children. I eat, I play, I laugh" (Kumar et al 2019).

Identify antecedents and consequences

Consequences are the outcomes of the Leprostigma concept and occur as a result of the concept (Walker & Avant 2005) (Fig.3). It demonstrates the relationship between the antecedents and the process of Leprostigma occurrence and its consequences.

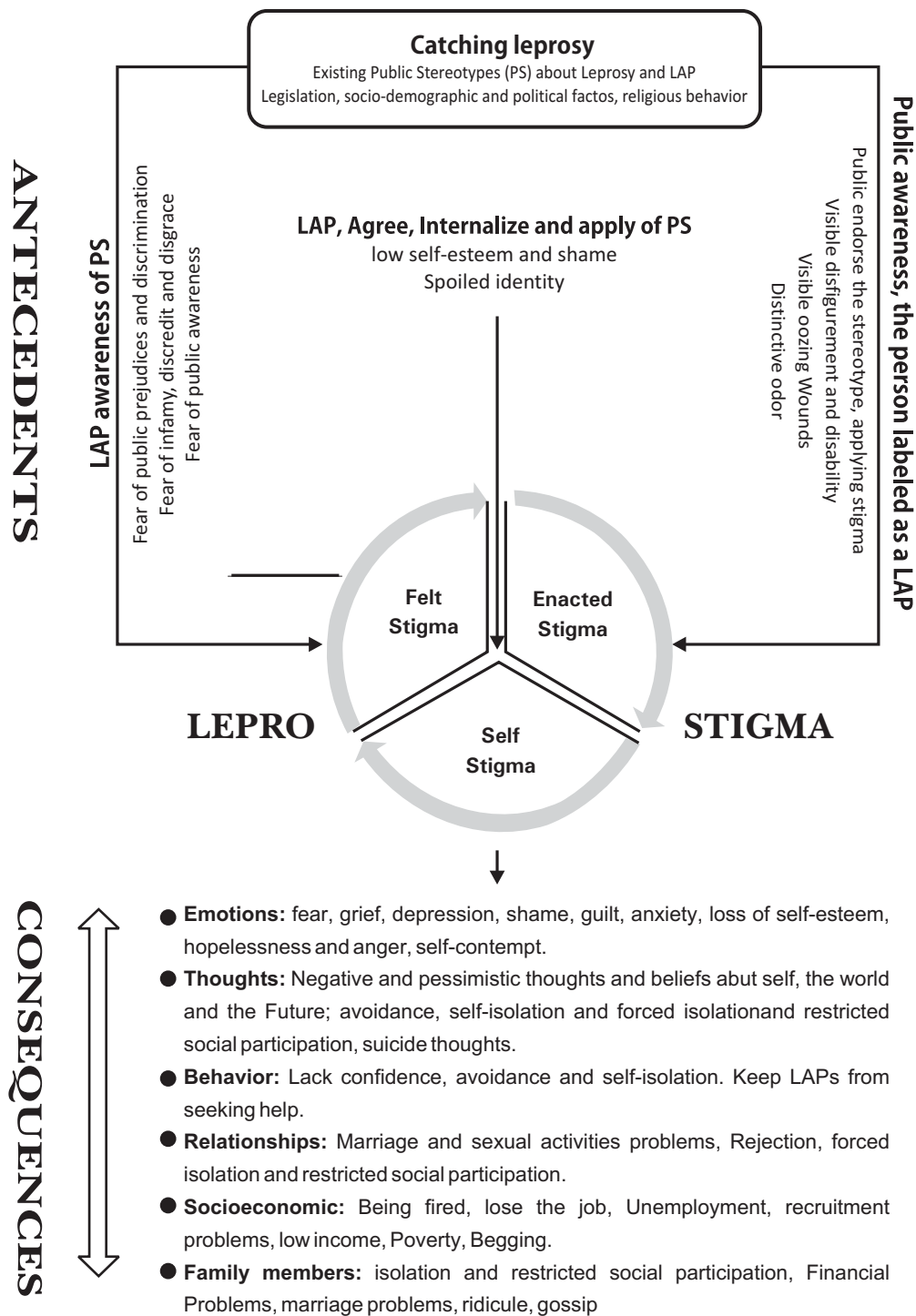


Fig.3. Conceptual model of Leprostigma

Define empirical referents

The last step of Walker and Avant's model is defining empirical referents to observe if the concept is present and measures of the defining attributes (Walker & Avant 2005). The results revealed that Leprostigma is an abstract concept with multidimensional aspects. Therefore, it is difficult to measure objectively, and no standard instrument has been developed for this purpose. However, Stafford and Scott believe norms are measurable, which means that stigmas can be studied empirically (Stafford & Scott 1986). Attributes of Leprostigma can only be measured by self-report.

Discussion

Leprosy has been plaguing humans since ancient times, and its name is associated with impairment, rejection, discrimination, and segregation. Leprostigma is a common and unfortunate historical fact. Literature has identified leprosy as the most stigmatizing of diseases (Cross & Choudhary 2005, Kazeem & Adegun 2011, Adhikari et al 2014a, Kumar et al 2019). In the past, patients were told that you are officially dead, they had to wear distinctive garments and used Warning clapper or horn (Grön 1973, Trautman 1984, Awofeso 2005, Bennett et al 2008, van Brakel et al 2019 a). Negative views on the character of the LAPs have found their way into literature (poetry and fiction), art (painting) and later cinema, and LAPs have had negative roles in several films such as Ben-Hur (1959), and Papillon (1973), Braveheart (1995). Dogliotti (1979) in his analysis of the different cultures' literature on leprosy, expresses "disgust and rejection" as a dominant attitude. As a result, leprosy is a social issue that exposes LAPs to Leprostigma rather than being an infectious disease or a health issue (Singh et al 2019).

Rafferty state that stigma is "hard to define and measure, being a complex reality made up as it is

from a mixture of belief, attitudes, and behaviors" (Rafferty 2005). Stafford and Scott argue that the reason why it is difficult to approach the study of stigma with much confidence is that there are so many kinds (Stafford & Scott 1986). The Oxford English Dictionary defines the origin of the term stigma as a mark or dot made by a pointed instrument. Later, the stigma concept became more common and was referred to by other features that were embarrassing, shameful, and disgusting. As summarized in Table 1, stigma has been defined differently by different authors, mostly pointing to negativity comprising of traits and processes which affect the social life of individuals adversely.

Leprostigma is a global phenomenon with social construction (Van Brakel 2003) because the stigma is a negative response to human differences (Augustine et al 2011). Leprostigma emerges a broad spectrum of unfair and negative consequences through a dynamic process (van Brakel 2003, van Brakel et al 2011). It should be noted that the experience of Leprostigma depends on the LAPs perception, not necessarily on whether the perception was accurate (van Brakel et al 2011). Developing studies on the de-stigmatization of LAPs confirm the Leprostigma exists world widely. (Marahatta et al 2018, Tosepu et al 2018, Dadun et al 2019, Lancet 2019, Singh et al 2019, Sottie & Darkey 2019, van Brakel et al 2019).

In a general category, stigma may be conceptualized in terms of self-stigma or public stigma (Heijnders 2004, van Brakel et al 2012). Self-stigma is as follows, holding negative views about oneself based on negative association difference. The public stigma associated with the general public's endorsement of prejudice and discrimination toward persons with differences (Weiss 2008, van Brakel et al 2012, Sheehan et al 2017).

In the Hidden Distress Model, Scambler describes two new stigmas, including enacted-stigma and felt-stigma. Based on this model for LAPs with visible disfigurement and disability, enacted-stigma occurs. However, LAPs still have no apparent manifestations and have begun or even completed treatment; fear of discrimination develops felt-stigma and hides the disease from fear of leprostigma. This stigma can also impede adherence to treatment. The fear caused by felt-stigma can be as destructive as the enacted stigma (Scambler 1998).

In this concept analysis, it is observed that Leprostigma occurs in three primary forms. It is important to know that the kinds of Leprostigma have overlapping values and affect each other. LAPs Lay suffer from more than one type of Leprostigma or endure all three types of Leprostigma at the same time (mixed Leprostigma) (Adhikari et al 2014b, Sheehan et al 2017). LAPs may fall into another stigmatized group, and their Leprostigma could be doubled, such as physical disability and poverty stigma. These situations can lead to the intensification of Leprostigma. The person who labeled as a LAP undergoes Leprostigma. LAPs are forced to leave work due to illness and disability or lose their job because of a negative employer attitude. These consequences reduce LAPs self-esteem and lead to decreased access to social and financial support resources. Unemployment causes poverty, and poverty also strengthens Leprostigma (van Brakel et al 2012, Lusli et al 2015, Dadun et al 2019). The lack of social support undermines LAPs social identity and self-esteem (Rafferty 2005). As the cycle continues, the leprostigma is reinforced. Leprostigma can also advance to family members and other people associated with the LAPs (Goffman 1963, Sheehan et al 2017).

In the process of stigmatization in leprosy as the

"concealment cycle," Hyland described that LAPs try to maintain their social integrity. First, they try to conceal their illness as much as possible and use hide techniques such as silence and storytelling. However, LAPs cover up or avoid presenting in public due to social curiosity on their developed leprosy symptoms. LAPs feel threatened at this period and enter the withdrawal phase, reacting by leaving home alone and going elsewhere for work. In the following, LAPs informed about the rumors and words of others behind them, the probability of public exposure. This stage, called public silence/private slander, can take a long time and allow the patient to complete treatment. LAPs stay in "the wait and see the state," and they remain within the community. But if "public exposure" does occur, society will label the patient by "sickness," and LAPs will have varying levels of isolation and social deprivation depending on the social context (Hyland 1993).

The social-cognitive model is useful in explaining the process of Leprostigma experience. According to this model, stigma is comprised of three structures: stereotypes, prejudices, and discrimination. Stereotypes (cognitive structure) are an over-generalized belief and public attitudes about LAPs. Stereotypes encourage prejudice. prejudice (affective structure) is an emotional reaction, and affective feeling towards LAPs (Following the endorsement of public views). Discrimination (behavior structure) is a behavior that results from two previous structures (Sheehan et al 2017). Fig.4 illustrates an example of the public and Self-Leprostigma formation.

Conclusions and way forward

This concept analysis has aimed to improve knowledge and understanding of Leprostigma showed that Leprostigma is a complex concept that is evolving. At first, the concept emphasized

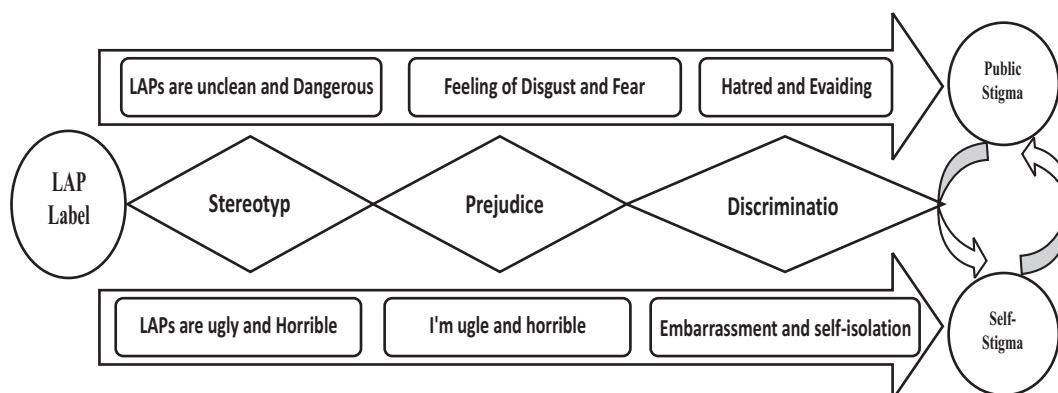


Fig. 4: Leprostigma formation according to the social-cognitive model

only the characteristics of LAPs that separated them from the "ideal person," but now the concept emphasizes the social aspects of Leprostigma. The etiology of stigma differs among conditions and cultural settings. The likely reason is that its stereotypes are a culture-specific phenomenon. For example, while in Nepal, fear of transmission was a major cause of Leprostigma, in Thailand, leprosy was thought to be hereditary, and people have no fear of contact with LAPs (Sermitirong & van Brakel 2014). The consequences of Leprostigma are similar across conditions and cultures. Because of this resemblance, similar stigma-reducing programs can be useful in various conditions and cultures (van Brakel 2003, van Brakel 2006, Weiss 2008). Meanwhile, it is possible to eradicate Leprostigma due to the dynamic nature of Leprostigma. Stafford and Scott state that stigma does not necessarily inhere in behaviors or kinds of person. Therefore, it can be changed (Stafford & Scott 1986).

This concept analysis can apply to research, concept development, and nursing practice and can be used by researchers and clinical staff. Because Leprostigma has become a social phenomenon with multiple consequences and profound effects, nurses and other professionals

must know the pervasive nature and components of Leprostigma. Understanding Leprostigma promotes nursing practice by help nurses to individualize care and allows nurses to evaluate their beliefs and values in interacting with LAPs. Understanding Leprostigma is useful for semantic integration and increased stability in the use of the concept, dialogue, and literature. This concept analysis will help health professionals develop de-stigmatization programs and improve the interaction between health professionals, LAPs, and their families.

Leprostigma developed from a primitive concept with an emphasis on attributes of LAPs to the concept with a complex social structure and occurs in a broad spectrum of unfair and negative consequences through a dynamic process. This concept analysis can improve the implementation of more extended studies and the development of research tools as well as practice. As a result, it can be recommended that the term "Leprostigma" use instead of various leprosy-related stigma terms.

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