# Literature Review: The Influence Of Illness Perceptions On Patients With Diabetic Foot Ulcer

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**Abstrak:** The urgency on the high incidence of Diabetic Foot Ulcer (DFU) around the world especially in Indonesia bring a big question, what are the factor that cause this phenomenon. Evidence from the numerous research bring a new finding on the role of illness perception and it significance on DFU. The concept of illness perceptions also gaining a huge interest on nursing research and has been founded on multi-level nursing theoretical framework. This tudy aim to identify the concept of illness perceptions and the Illness perceptions framework in order to provide a comprehensive guideline to understand the phenomena of DFU in Indonesia. A literature review was conducted using multiple sources of academic journal. The concept of illness perceptions has been reviewed and its significance on DFU has been identified. Moreover, an effective method of a future study on illness perceptions among patients with DFU has been proposed.

Keywords: Diabetic Foot Ulcer, Illness Perceptions, Indonesia.

# 1. INTRODUCTION

Diabetic foot ulcer (DFU) is one of microvascular complications which occurred approximately 15% in diabetic patients during their lifetime [1]. Once the patients have DFU, they are prone to infections; as a result, hospital admission is required [2]. However, only two-thirds of the ulcers are ultimately healed and more than 28% of those will lead to an amputation. Moreover, DFU patients expend 20% to 40% of the health resources for diabetes [3]. In conclusion, DFU considered to be a big problem in worldwide.

Indonesia as one of the developing country has the prevalence of DFU approximately around 7%-24% [4]. This number was considered high compared to other countries such as Nigeria [5], Malaysia [6] and Europe [7]. The details are in table 1.

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No	Country	DFU incidence
1	Indonesia	7-24%
2	Nigeria	9.5%
3	Europe	3%
4	Malaysia	1.5%

Table 1. Comparison of DFU Incidence

The occurrence of DFU may worsens the diabetic patients' conditions [8], due to DFU, the length of time for healing takes several weeks or months [9] which can cause the patients face numerous problems in long time and impact not only physical aspect but also emotional, socioeconomic, and spiritual aspects [10,11,12]. For the physical aspect, the patients will have limitations of daily activities regarding pain and difficulty in movement [13]. In the emotional aspect, pain and immobility affect the patients' emotion, such as depression and anxiety [14]. Moreover, physical limitation is a significant factor that limits the patients' socio-economic aspect. They may feel isolated and discriminated from their family and society [15]. Furthermore, the patients tend to lose the job, work ineffectively and absenteeism which leading to reduce of productivities [16]. They also confront financial burdens due to medical expenses and transportations from home to medical services [12]. For the spiritual aspect, the patients will be unable to attend spiritual activities due to physical limitations and embarrassed feelings [17]

There are numerous factors that developed the ulceration in diabetic patients. According to American Diabetic Association (ADA) [18], the main contributor factors for ulceration among diabetic patients are peripheral neuropathy (PN), peripheral vascular disease (PVD), poor glycemic control, visual impairment, smoking, foot deformities, diabetic nephropathy, previous amputation, and past ulcer history. Recent studies were discovered other significant factors that can be divided in five groups. The first group is demographic factors such as age [19], gender [20], duration of diabetes [21,22], body mass index [22], insulin use [4], education level [23], socioeconomic status [24] and rural area [19]. The second group is complication factors

such as PN [25], PVD [20], foot deformities [25], calluses [26], and hypertension [20]. The third group is behavior factors such as daily foot inspection [27], footwear adherence [24], smoking or tobacco use [24] and poor glycemic control [20]. The fourth group is past history factors such as previous amputation [28] and previous ulceration [29]. The last group is spiritual factors which is belief to the God [4]. These factors were commonly founded in numerous nursing research. However, little we know that there is one new factor that rarely explored in scope of nursing research.

Interesting finding from Vedhara et al., 2014 discovered a new factor that may associated with incidence of DFU. Illness perceptions was founded as a significant factor that influence the way patients manage their behavior and it contributions in health outcomes. Illness perceptions has been founded has a major influence on the way patients perform self-care behavior and significantly influence the health outcome patients with DFU. In addition, the concept of illness perceptions has been widely used in numerous nursing research. It refers to patients' own beliefs regarding their disease based on their personal experience of sign and symptoms, previous knowledge, culture and other social factors [31,32] These conditions are influencing patients' health behavior performance and contribute to their health outcomes [33]. In general, a negative illness perceptions are related to negative health behavior and negative illness management [34], for instance; a patient with negative illness perceptions of each patient is unique and might be different, nurses need to understand how to deliver the nursing care appropriately to avoid a miscommunication. Instead of judge the patients as a "noncompliant", the nurse needs to investigate what are the factors that influencing their patients' illness perceptions and analyze what is something in common that can be share between the patients and nurse [36].

Interview on 5 subjects from pilot study in outpatient department in referral hospital in Indonesia reveal interesting findings on illness perception among patients with DFU. Belief on types of diabetic that divided into two types which are wet and dry diabetic was existed and some patients were believed that DFU may happened on someone who have a wet type of diabetic. Moreover, some subjects were believed on mixing the herbal and traditional medication to treat their DFU. Those are a few examples of incorrect perceptions on patients with DFU. Further exploration on illness perceptions should be done in order to clarify the misunderstanding.

# 2. METHOD

A literature review was conducted using the following search resources: Medline, Science Direct, PubMed, and Google Scholar. The following terms were entered: illness perceptions, illness perceptions on diabetic foot ulcer patients.

#### 3. **RESULTS**

The domain of illness perceptions framework were identified and analyzed for its significance with DFU. Moreover, the impact of illness perceptions on patients with DFU has been founded.

# 1. ILLNESS PERCEPTIONS FRAMEWORK

There are several frameworks that explained the phenomena of illness perceptions in nursing. One of those famous frameworks that widely used in nursing research is Common Sense Self-Regulatory Model (CSM) by Leventhal and colleagues in 1970 and 1980. CSM is a multi-level framework that not only constructs individual vulnerability and illness severity, in the other hand; it also distinguishes between prototype (memory structure) and representations (the mental models which activate at certain instances in time). Prototype is related to patients' knowledge that based on history of somatic sensations and physical experience. It selfrepresentation or belief about structure and function of their body when healthy or ill, treatment and illness based on their understanding. These conditions are dynamic and might be updated by daily life through observation, social engagement, mass media and other abstract sources of information. After the prototype identify the experience of sign of ill conditions, the representations will be activated and create particular disease diagnose based on patients' understanding [37]. These representations have eight main dimensions of the cognitive and emotional representation that consist of (1) identity, it refers to a label or name and perceptions of related to acquired symptoms of the illness; (2) timeline, it refers to individual perceptions regarding the duration of their illness (it might be acute or chronic or cyclical); (3) cause, it associated with personal belief about the factors that provoked the illness; (4) consequences, is relate to individual assumption of the impact of the illness to the holistic aspect (economic, social, or physical aspect); (5) perceived control dimension encompasses assumption regarding individuals' think about their ability to do something to reduce the illness; (6) treatment control, beliefs regarding the effectiveness of treatment to control the illness (7) coherence is dimensions that interpret the ability of individuals in understanding their illness; and (8) emotional representation of the illness [38]

#### 2. ILLNESS PERCEPTIONS AND DFU

Considering the fact that DFU as a chronic disease, it makes the DFU patients need an extra care in order to prevent the occurrences of it. The patients need to have a good preventive self-care to avoid behaviors that may cause a break in the skin of the feet and perform a daily foot care [39]. Thus, the DFU patients need to have a good self-management. Furthermore, the illness perceptions of patients with DFU significantly affect the way patients with DFU manage their conditions [40]. Numerous studies have been found the evidence of each dimension of illness perceptions in term of influencing the way patients manage their behavior and it contributions in health outcomes. The dimensions of identity and cause influence the way patients perform selfcare behavior. The broader knowledge of the patients regarding sign and symptoms and risk factor for DFU will influence the way patients engage in certain behavior [30]. The dimensions of timeline and consequences are the main factor for increase the awareness of the illness. A greater concern of the illness will lead to the fear of the disease and may increase the adherence to perform a self-care and engage to the health treatment intensively [41]. The perceived control component is related to patients' re-assessment of their condition. In particular, patient tend to consider the importance of their illness condition when they think they able to control their illness. The sixth dimension, treatment control beliefs is a major factor in treatment adherence and value of interaction between patients and health care provider [42]. Patients with DFU may feel hesitate to perform foot care and avoid to meet the nurse since they did not have positive perceptions in treatment control. The seventh dimension that known as illness coherence has a significant relationship with better self-management. This may be happened due to the greater understanding of the disease make the patients have more ability to perform an appropriate self-management program [40]. The last dimensions which is emotional representations have a unique role in influencing the healing time among patients with DFU. A study discovered that emotional representations were a predictor of time taken to heal, this study found that negative emotional representations increased the ulcer healing time. In conclusion, all of dimensions of illness perceptions have an important role in term of influencing the behavior and health outcome among patients with DFU [43].

# 3. DEVELOPMENT OF ILLNESS PERCEPTIONS INSTRUMENTS

There are several versions of standardized instruments to measure illness perception based on Leventhal's CSM in nursing research. The first development of illness perceptions instruments was in 1996. Weinman, Petrie, Moss-Morris and Horne published the first Illness Perception Questionnaire (IPQ) [44]. The IPQ is concern in assessing cognitive representations of illness, as a result; it consists of 25 questions that cover five cognitive dimensions. The first part is illness identity, the patients will indicate how frequent they experience the symptoms as part of their illness. The second part is cause dimension that consist of some risk factors could be identify by the patients as determinant of their illness. The third part is time-line that consist of three questions about the illness whether it will be acute or chronic or cyclical. The fourth dimension is consequences that consists of seven questions about how patients consider the impact of their illness. The last dimension in IPO is control/cure that consist of six questions about the belief of the patients in term of the way patients have an expectation on their treatment and their ability to control their illness. Moreover, the IPO has been tested in variations of chronic disease such as myocardial infarction, chronic fatigue syndrome, rheumatoid arthritis, diabetes, renal disease and asthma. The result of validity and reliability of IPQ also shown a good level of both internal consistency and test-retest reliability. In validity test, IPQ shown a good consistency in concurrent and for discriminant validity it shown a distinct presentations and effects in different illness. In addition, IPQ also can predict the illness representation with a subsequent follow-up. In conclusion, IPQ could be a suitable instrument to measure illness perceptions in various disease.

However, a feedback from acquired episodes of research that use the IPQ has led to the necessity to extend the scope of the existing subscales. Therefore, Moss-Morris, et.al (2002) added three components in the new version of IPQ. The domain of cure-control has been revealed to be separated part into self-efficacy beliefs and beliefs in the treatment or recommended advice. Moreover, illness coherence subscale was added to assess the degree of patients' illness perceptions provided comprehensive understanding of the illness. Furthermore, since the original version of IPQ was only assess the cognitive representative of the illness, as a result; it was failed to assess the emotional responses and it becomes a major limitation of the original IPQ. Thus, Moss-Morris and team add an emotional subscale to identify the emotional responses that resulted from the illness. In addition, to validate the structure of revised version of IPQ (IPQ-R), Moss-Morris and team conducted several methods of validity and reliability test. The first method is structural validity and reliability test. The structural validity was conducted by principal component analyses on the preliminary data collected from 711 patients, as a result the content of each subscales is success to confirm the CSM theoretical framework. The internal reliability also shown a good consistency in all the subscales. Another validity and reliability test also has been conducted including discriminant validity, known group validity, predictive validity and test-retest reliability, as a result; all of those tests were had good outcome. Finally, Pearson's correlation coefficients were computed to analyze the inter-relationship between the IPQ-R subscales and the results shown that all the subscales have a positive relationship one to another. In conclusion, IPQ-R has been extended to be a more appropriate instrument and able to explore further regarding how illness makes a sense among individuals.

In the other hand, IPQ-R that has been expanded have a meaningful limitation in its application on particular illness condition. The length of the IPQ-R (around seventy items), may take a long time to complete, as a result; it becomes a burden for patients with a very ill condition and elderly [45]. Thus, another development of shorter version of illness perception instrument has been conducted by Broadbent, Petrie, Main and Weinman in 2006. This version is namely as Brief Illness Perception Questionnaire (BPIQ). The BPIQ covers both cognitive and emotional responses of the illness and it consist of one open ended question that dealing with causal representation and eight quantitative questions that respondents answer on a scale of 0 to 10. This will decrease the burden among the subjects and help them quicker to finish the questionnaire. Moreover, the BPIQ demonstrated good result in several kinds of validity and reliability test and it also applicable in various kind of disease [45].

Finally, three different version of illness perceptions measurement provide a different function in particular situation. Each of the measurements has their own limitations. The IPQ is might be good to measure the illness perceptions. However, it cannot explore the emotional aspect of the patients. The IPQ-R is cover all the domain of illness perceptions, nevertheless; the numbers of the questions can be a burden for the patients and it need a very long time to complete. The BIPQ with a short and simple questions may be effective to be used in outpatient department where the participants need to pay attention to their treatment and they only have a short time to complete the instrument [46]. Anyhow, the simplicity of BIPQ might cannot give the detailed analysis on illness perceptions. However, this problem can be solved by performing a follow up study such as qualitative study by in depth interview.

# 4. RELATED RESEARCH OF THE SIGNIFICANCE ILLNESS PERCEPTIONS ON DIABETIC FOOT ULCER AND OTHER CHRONIC ILLNESS

Numerous studies have been noted the significance of illness perceptions in the outcome of chronic illness [46,47,48]. In these studies, it was founded that illness perceptions have an important role in influencing individuals' behavior to take an action and may predict the health outcome. A prospective observational study has been conducted to test the correlation between illness perceptions and mortality in DFU patients. The baseline data collection has been conducted between January 2002 to January 2007 by using Brief Illness Perceptions Questionnaire (BPIQ) that developed based on Leventhal's CSM. The sample that they used in this study was patients type 1 or type 2 diabetes mellitus and a foot ulcer from outpatient podiatry clinics secondary care in UK [49]. The result of this study revealed that patients with poorer understanding of their illness (illness coherence) are related to the death incidence. This may suggest that measurements on illness perceptions not only can improve understanding of correlation between belief and mortality, but also may integrated into intervention to improve survival. However, this study has been failed to give a clear explanation why illness perceptions can increase the mortality among DFU patients. The researcher suggests that qualitative study or using more detail questionnaire such as IPQ-R will help to enlighten the illness perceptions study.

Another prospective study revealed significant impact of illness perceptions in influencing self-care behaviors among DFU patients. The participants in this study were completed the Brief Illness Perceptions Questionnaire and foot care subscale questionnaire as a baseline data (week 0) and followed up in 6, 12, and 24 weeks respectively. At baseline, clinical and demographic data also collected on all participants. Consequently, linear regressions examined the significant addition of perceptions at baseline to sequential foot self-care behaviors, controlling for past behavior and clinical and demographic factors that affect foot self-care. The result of this study assumed that illness perceptions is independent predictors of foot self-care behaviors [30]. This study suggests that intervention that developed based on illness perceptions in DFU patients will help to improve a foot self-care behavior among DFU patients. However, we need to explore deeply the illness perceptions on certain population before we can develop an intervention appropriately. Thus, descriptive study of illness perceptions may benefit the nurses to develop such an intervention to improve foot self-care behaviors.

Moreover, a study discovered the significance of illness perceptions on healing time in venous leg ulcers. The prospective observational study was conducted on 63 patients with venous leg ulcers for 24 weeks, the number weeks to heal and rate of change in ulcer are were observed during that time. The illness perceptions were measured with Revised Illness Perceptions Questionnaire. The statistic result of this study showed that patients with negative perceptions and negative emotional representation about the ulcer have a slower rate of change and longer weeks to heal [43]. This study adds the evidence that illness perceptions is strongly impact the clinical outcomes.

Furthermore, another study about illness perceptions on several chronic diseases highlighting the role of illness perceptions in chance of survival [46], treatment adherence [50], clinical and psychosocial outcomes [48], and influence the quality of life [41]. These related studies are strong evidence that illness perceptions have a wide role in influencing human behavior and it has a big contribution on clinical outcomes.

Those studies were brought meaningful finding to us in term of how far the 'perceptions' could manipulate and bring major influence on health outcomes. As we seen, there are several studies existed about illness perceptions and DFU in other countries. However, there is no studies related with perceptions in DFU have been conducted in Indonesia. The previous interview was conducted in small number of patients. It needs a substantial number of patients to get the clear picture of illness perceptions in patients with DFU in Indonesia. Moreover, this could bring lot of data and can be used to distinguish a misunderstanding of DFU among nurses and the patients. At the end, it can be useful to develop the intervention to improve the illness perception and may reduce the incidence of DFU in Indonesia.

#### 4. CONCLUSIONS

Illness perceptions seems bring an important value on DFU. Thus, exploring illness perceptions in patients with DFU become something that have to be done, especially in Indonesia. The existence of the various measurement of illness perceptions make it possible to be used and adjusted in wide range of settings. However, since that patients with DFU may have a physical limitation which it will burdening them when the questionnaire has a very long item, therefore; a quick and short assessment like BIPQ might be preferred rather than the IPQ-R. Then, the interview might be performed later to clarify and give further explanations of the result of BIPQ.

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