

Illness representations in chronic diseases: A literature review

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ABSTRACT

The prevalence of chronic illnesses, including hypertension, stroke, heart failure, diabetes mellitus, cancer, and chronic kidney disease, is rising globally. The primary causes of death and disability among patients are these kinds of illnesses. Consequently, healthcare professionals must focus more on these illnesses. This study aims to collect and examine articles related to illness representations in chronic diseases. A search for relevant literature was conducted using the following keywords: "Illness Representations," "Female," "Patient," and "Chronic Diseases" across three databases: PubMed, Taylor & Francis, and Science Direct. Time for articles with searches published from 2018 to 2023. Five articles were selected after screening 762 total articles in accordance with the PRISMA flowchart guidelines. The findings indicated that different populations have different representations of chronic diseases and that these diseases are reflected in the course of illness. It is important to take into account various factors that influence the way illnesses are portrayed, including stable health conditions, knowledge, perception, the duration of the illness, and marital satisfaction. It should be possible for future research to examine how illnesses are portrayed as chronic diseases in greater detail using a range of research designs.

Keywords: chronic diseases; illness representations

ABSTRAK

Prevalensi penyakit kronis, termasuk hipertensi, stroke, gagal jantung, diabetes melitus, kanker, dan penyakit ginjal kronis, meningkat secara global. Penyakit ini merupakan penyebab utama kematian dan kecacatan pada pasien. Oleh karena itu, tenaga kesehatan harus lebih fokus pada penyakit ini. Penelitian ini bertujuan untuk mengumpulkan dan mengkaji artikel tentang representasi penyakit pada pasien dengan penyakit kronis. Pencarian literatur yang relevan dilakukan dengan menggunakan kata kunci berikut: "Illness Representations", "Female", "Patient", dan "Chronic Diseases" di tiga database: PubMed, Taylor & Francis, dan Science Direct. Rentang waktu pencarian artikel yang dipublikasikan mulai pada tahun 2018 hingga 2023. Lima artikel terpilih setelah menyaring dari total 762 artikel sesuai dengan pedoman flowchart PRISMA. Hasil review menunjukkan bahwa populasi yang berbeda memiliki gambaran penyakit kronis yang berbeda, dan penyakit ini tercermin dari perjalanan penyakitnya. Penting untuk mempertimbangkan berbagai faktor yang mempengaruhi representasi penyakit, termasuk kondisi kesehatan yang stabil, pengetahuan, persepsi, durasi penyakit, dan kepuasan pernikahan. Penelitian selanjutnya dapat meneliti bagaimana representasi penyakit pada pasien dengan penyakit kronis secara lebih rinci dengan menggunakan serangkaian desain penelitian.

Kata kunci: illness representation; penyakit kronis; representasi penyakit

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INTRODUCTION

Chronic diseases remain a significant concern for the government due to their increasing rates of disability and mortality every year. The prevalence of chronic diseases is quite significant worldwide, Southeast Asia, and Indonesia. According to the World Health Organization's (WHO) 2021 data, chronic diseases such as heart disease, stroke, diabetes, and cancer account for about 71% of death worldwide. Chronic diseases are also become the leading cause of death in Southeast Asia, including Indonesia. In 2019, non-communicable diseases such as heart disease, stroke, diabetes, cancer, and chronic respiratory disease, caused approximately 63% of deaths in Southeast Asia. The prevalence of chronic diseases in Indonesia has been increasing from year to year, as indicated by the Riskesdas 2018 (Basic Health Research) data. In 2018, 15.6% of the Indonesian population suffered from diabetes, 7.1% had hypertension, 2.3% had cancer, and 1.5% had a stroke. The three provinces with the highest prevalence of chronic diseases were DKI Jakarta with a prevalence of 17.6%, where hypertension was prevalent at 10.4%; West Java with a prevalence of 14.2%, where hypertension was prevalent at 9.7%; and Central Java with a prevalence of 14.2%, where hypertension was prevalent at 8.1% (Depkes RI, 2018). These data indicate that chronic diseases are a serious health problem, and effective prevention and management efforts are required to improve the health and quality of life of the population.

The study of chronic diseases is in line with the roadmap of the Nursing Program at the Faculty of Health Sciences, Universitas Muhammadiyah Surakarta (UMS), which focuses on chronic care nursing (UMS, 2023). UMS's Nursing program has actively published research on chronic diseases, including heart diseases such as hypertension, heart failure, diabetes mellitus, and cancer (Center for Disease Control, 2023). Cardiovascular disease is one of the leading causes of death worldwide, and stroke, a cerebrovascular disease, is also included in cardiovascular disease and is associated with vascular disorders (World Health Organization (WHO), 2023). It is known that there are differences in the chronic diseases experienced by male and female, with some chronic diseases posing a higher risk to female than male (Cordonnier et al., 2017). For instance, most patients with hypertension are female, had low physical activity, and they sometimes voice dissatisfaction with their health (Rahayu, S., Malvasari, S. P., & Viani, 2022; Süslü, M. S., & Perçinci, 2023). Since the duration of the patient's care is directly correlated with knowledge, involving the family is also crucial. The better the family's knowledge, the more positive their attitudes and ways of caring for patients will be. As a result, illness representation can be handled sooner (Anggraini, 2022). Healthy lifestyle choices ought to be promoted and maintained (Utami, N. P., Ayuningtyas, C. E., & Pertiwi, 2023). This highlights the importance of healthcare providers taking preventive measures, reducing cases, or controlling diseases.

Studying illness representation is crucial in order to develop effective preventive and treatment strategies. Illness representation refers to a construct of disease representation that includes disease identity dimensions, causative factors, periods, impacts, and cure rates (Fitri RA, 2011). Studies on illness representation in patients with hypertension have explored their understanding of the disease, symptoms, causes, duration, complications, and treatment options (Setyorini A, 2020). Studies have also shown that patients receiving long-term therapy for ischemic heart disease have higher quality of life when they have high levels of self-efficacy (Kristinawati et al., 2023). Although these studies have yielded slightly different results, they both aim to improve our understanding of illness representation in patients, which is important for disease management. For example, Benson relaxation therapy has been shown to reduce anxiety in patients with chronic kidney disease (CKD) undergoing hemodialysis (Anisah, I. N., & Maliya, 2021). The differences in results may be attributed to variations in research methods used. It is worth noting that illness representation is closely related to the development of a patient's disease (Richardson EM, Schuez N, Sanderson K, Scott JL, 2017).

Therefore, based on the above explanation, it is important to conduct research on chronic illnesses in female in order to increase understanding of risk factors and effective management strategies. This research can help in developing more targeted prevention and treatment programs to improve the health of patient with chronic illnesses. The researcher is interested in conducting a study with the aims to gather and analyze articles related to illness representations in chronic diseases.

RESEARCH METHOD

This paper was written as a literature review, with the method used being a narrative of research results from around the world related to this topic. The data search was carried out systematically using computerized database sources obtained from PubMed, Taylor & Francis, and Science Direct, with the keywords used being "*Illness Representation*" OR "*Illness Representations*" AND "*Female*" AND "*Patient*" AND "*Chronic Diseases*". The total articles obtained from the search engines mentioned were 762 articles (PubMed: 475, Elsevier: 6 and Science Direct: 281). They were analyzed using the PRISMA (Preferred Reporting Items for Systematic Review and Meta-Analysis) diagram showed in Figure 1, resulting in 5 articles that met the inclusion criteria used. The articles were in English, using a quantitative descriptive research design and qualitative phenomenological research, and published between January 2018 and May 2023 regarding illness representation in chronic diseases. A summary table based on article extraction results is presented in Table 1.

Article Selection

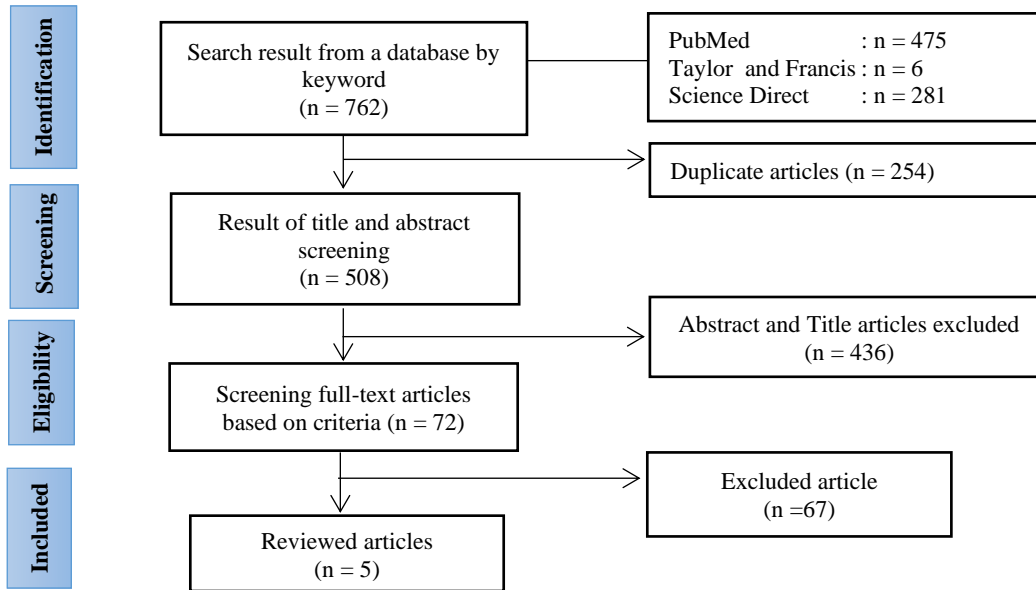


Figure 1. PRISMA Diagram

RESULTS AND DISCUSSION

This literature review included five articles that satisfied the inclusion requirements. The paper was produced by searching three databases (Science Direct, Taylor & Francis, and PubMed) between the years of 2018 to 2023. The reviewed article is the outcome of five studies, as shown in Table 1. Subsequently, the five articles were examined and compared for similarities and differences.

The representations of illness are the focus of these five articles, though other variables are also studied. Of the five articles, Brand et al. (2021); Kajiwara, Y., & Morimoto (2023); Rivera et al. (2018) all present cross-sectional studies. The Illness Perception Questionnaire-Revised (IPQ-R) is the same questionnaire used in three articles (Kajiwara, Y., & Morimoto, 2023; Rivera et al., 2018; Szabó-Bartha, A., & Mirnics, 2021). CKD patients are the same population in both articles (Kajiwara, Y., & Morimoto, 2023; Rivera et al., 2018). Two publications on the incidence of cancer (Brand et al., 2021; Kugbey, N., Asante, K. O., & Meyer-Weitz, 2020).

In the meantime, there are a wide range of differences amongst the five articles. **First**, Kajiwara, Y., & Morimoto (2023) is the newest article, and Rivera et al. (2018) is the oldest. **Second**, research was carried out in a number of nations, including Ghana, Hungary, Germany, Japan, and the USA. **Third**, there were only two articles which is research by Brand et al. (2021) and Kugbey, N., Asante, K. O., & Meyer-Weitz (2020) with participants who were specifically female; the other articles included participants of both genders (Kajiwara, Y., & Morimoto, 2023; Rivera et al., 2018; Szabó-Bartha, A., & Mirnics, 2021). **Fourth**, the most participants were found in research by Kajiwara, Y., & Morimoto (2023) with a total of 212 respondents, 140 male patients and 72 female patients with CKD. Furthermore, research by Rivera et al. (2018) with 187 respondents consisting of 63 heart failure patients, 65 with CKD, and 59 with COPD. Research by Szabó-Bartha, A., & Mirnics (2021) with a total of 154 respondents (79 male 75 female). Research by Brand et al. (2021) with 101 female with pathogenic BRCA variants and the least is research Kugbey, N., Asante, K. O., & Meyer-Weitz (2020) with 11 respondents who received breast cancer. **Fifth**, the instruments in patients with cancer are using The Brief Illness Perception Questionnaire (BIPQ)-German Version. **Sixth**, different articles produce different outcomes when it comes to illness representation. Research by Kajiwara, Y., & Morimoto (2023) showed that Cluster 1 represents difficulty in understanding changes in conditions caused by disease and easily falls into misunderstandings (*timeline acute/chronic, personal control, and illness coherence*), Cluster 2 represents patients with disease conditions that impact their daily life and emotional responses (*identity, timeline acute/chronic, consequence, and emotional representations*), and Cluster 3 represents the ability to control and understand disease (*personal control, treatment control, and illness coherence*). Research by Rivera et al. (2018) mentioned that the stable group (few consequences, non-fluctuating pattern) had the fewest hospitalizations compared with the other two groups. Research by Kugbey, N., Asante, K. O., & Meyer-Weitz (2020) explained that three primary factors impacted in illness representations are their knowledge about breast cancer, perceived causes of breast cancer, and duration/cure of breast cancer. Research by Szabó-Bartha, A., & Mirnics (2021) indicated that marital satisfaction had a remarkable influence on the similarity of illness representations and the accuracy

of perceptions of partners' illness representations. Patients and their partners are more likely to form similar disease representations if the symptoms are obvious as in the case of asthma or lung cancer Research by Brand et al. (2021) with 101 female with pathogenic BRCA variants shows that disease representations play an important role in psychological distress. Adults who are more positive have better physical and mental health (Qamar, S., & Yaqoob, 2023). Therefore, it can be underlined that different populations have different representations of illness among patients with chronic diseases. Numerous variables, including knowledge, perception toward the illness, duration of illness, history of previous illnesses, and more, affect this.

Table 1
Article extraction results

No	Author	Year	Country	Research Title	Objective	Design	Sample	Instruments	Results
1.	Yuki Kajiwara, Michiko Morimoto	2023	Japan	Identification of illness representational patterns and examining differences of selfcare behavior in the patterns in chronic kidney disease	To examine what kinds of representational patterns are present in patients with CKD before the start of dialysis	Cross-sectional descriptive approach	212 CKD patients	The Illness Perception Questionnaire-Revised (IPQ-R) to assess illness representation. IPQ-R dimension consist of identity, timeline acute/chronic, consequence, personal control, treatment control, illness coherence, timeline cyclical, dan emotional representations. The Japanese Chronic Kidney Disease Self Care to assess self care behavior	There are three patterns of representation among three cluster of CKD patients. Cluster 1 represents the difficulty of making sense of the changed condition caused by the disease and easily falling into misunderstanding (<i>timeline acute/chronic, personal control, and illness coherence</i>), Cluster 2 represents patients with disease conditions that have impacted their daily life and emotional responses (<i>identity, timeline acute/chronic, consequence, and emotional representations</i>), and Cluster 3 represents the controllability and understandability of the disease (<i>personal control, treatment control, and illness coherence</i>). Emphasis on disease representation is required, as evidenced by research that also found variations in self-care behavior based on patterns of disease representation.
2.	Eleanor Rivera, Colleen Corte, Alana Steffen, Holli A. DeVon, Eileen G. Collins and Pamela J. McCabe	2018	USA	Illness Representation and Self-Care Ability in Older Adults with Chronic Disease	To determine whether belief about one’s chronic disease (illness representation) are associated with self care activation, emergency department visit, or hospitalizations.	Cross-sectional design	187 patients (63 HF, 65 CKD, and 59 COPD)	The Illness Perception Questionnaire-Revised to measured perception of illness. The Patient Activation Measure to measured self-care activation	The study distinguished three groups based on unique disease representation profiles: the overwhelmed, stable, and confident groups. Despite sharing similar demographics, the groups' rates of hospitalization and self-care outcomes were different. In comparison to the other two groups, the stable group (few consequences, non-fluctuating pattern) experienced the fewest hospitalizations.
3.	Nuworza Kugbey, Kwaku Oppong Asante, Anna Meyer-Weitz	2020	Ghana	Illness perception and coping among women living with breast cancer in Ghana: an exploratory qualitative study	To explored the illness perceptions and coping strategies among women receiving care for breast cancer	A qualitative research design (phenomenology rooted in the interpretivist paradigm)	11 women receiving treatment for breast cancer	using semistructured in-depth interviews	Patients with breast cancer do not have enough factual knowledge about the disease, and the biopsychosocial model of illness shapes their perceptions about its causes. The fact that spirituality and social support are the primary coping mechanisms for patients suggests the need for psychosocial interventions tailored to their spiritual and psychosocial needs.
4.	Anett Szabo Bartha & Zsuzsanna Mirmics	2021	Hungary	Representations of chronic Illness in Patients and Their Partners	To provide a comprehensive picture of the burdens associated with the medical problems within a	A qualitative phenomenological study	154 patients (18 asthma bronchiale, 14 lung cancer, 47 hypertension, 42	The Illness Perception Questionnaire-Revised (IPQ-R)	Marital satisfaction has a remarkable influence on the similarity and accuracy of the perception of the partner’s illness representations. Patients with obvious symptoms, such as those of lung cancer or asthma, are more likely to create similar illness representations with their partners. The dimension of coherence has significant within-person

				relational perspective		myocardial infarction, 33 primarily bypass patients)		variations, as illness usually has a deeply personal meaning to both the patient and their partner.	
5.	Hannah Brand, Dorothee Speiser, Laura Besch, Julia Roseman and Friederike Kendel	2021	Germany	Making Sense of a Health Threat: Illness Representations, Coping, and Psychological Distress among BRCA1/2 Mutation Carriers	To investigated associations between illness representations, coping strategies and psychological distress	Cross sectional, observational, mono-center study	101 female with a pathogenic BRCA variant	The Brief Illness Perception Questionnaire (BIPQ)-German Version, the Brief COPE-German Version, the Cancer Worry Scale (CWS)	Females who had previously been diagnosed with cancer displayed patterns of illness representation that might be more upsetting than those who had not. The results imply that counseling professionals should be aware of how distressed females portray their illnesses. In this way, maladaptive thoughts associated with mutations can be detected, overcome adverse feelings and promote adaptive coping strategies.

CONCLUSIONS AND SUGGESTIONS

A careful examination of an extensive article that satisfies the inclusion requirements for the years 2018–2023 leads to the conclusion that heart failure, hypertension, CKD, myocardial infarction, primarily bypass patients, cancer, and COPD are the most prevalent chronic illnesses among patients. One frequently utilized tool is the Illness Perception Questionnaire-Revised (IPQ-R). The representation of illness among chronic diseases includes dimensions of identity, acute/chronic timeline, consequence, personal control, treatment control, illness coherence, cyclical timeline, and emotional representations. Chronic diseases are reflected in the outcomes of illness, and the representation of diseases varies among populations. It is crucial to consider factors that affect how illnesses are portrayed, such as stable health conditions, knowledge, perception, length of illness, and marital happiness. Future studies should be able to use a variety of research designs to look more closely at how illnesses are represented as chronic diseases.

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ETHICAL CONSIDERATIONS

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Conflict of Interest Statement

The authors declared that there was no conflict of interest.

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