

Research Article

Self-Care Management Education Using a Pocketbook on Illness Perception Improvement in Psoriasis Patients

Edukasi Manajemen Perawatan Diri Menggunakan Buku Saku pada Perbaikan Persepsi Penyakit Pasien Psoriasis

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ABSTRACT

Psoriasis is an autoimmune disease affecting the integumentary and organ systems. It impacts daily activities and degrades self-esteem. Meanwhile, there is a minimum amount of literature about self-care management education for Psoriasis. Pocketbooks can be used as an alternate learning tool for self-care management by making them more portable among patients. The aims are to foster a positive perception of illness and self-determination regarding Psoriasis. This study evaluated the effectiveness of providing self-care management education using a pocketbook on the illness perception of Psoriasis. The research employed a mixed-methods design, combining quasi-experimental and qualitative approaches. The study involves 30 participants diagnosed with Psoriasis. Participants are divided into two groups: a control and an intervention group. The Brief Illness Perception Questionnaire (B-IPQ) was utilized to assess the participants' perceptions of their illness before and after the intervention. A paired t-test was used to compare pre-test and post-test scores within each group. A two-sample t-test was employed to compare the mean differences between the control and intervention groups. The significance level was set at a p-value of 0.05. The interview data were transcribed verbatim using thematic analysis. The study indicates a difference in the illness perception of patients between control and intervention groups with a significance value of 0.000. Patients report that understanding triggers and management strategies allow for better health. Pocketbook is a practical education approach improving illness perceptions of Psoriasis. Recognizing triggers and adopting management techniques, patients are able to take steps to deal with flare-ups and improve their well-being.

Keywords: Illness perception, pocketbook, psoriasis, self-care management

ABSTRAK

Psoriasis merupakan penyakit autoimun yang mempengaruhi integumen dan sistem tubuh. Penyakit ini berdampak penurunan aktivitas sehari-hari dan harga diri. Sementara itu, literatur yang menjelaskan edukasi tentang Psoriasis dan manajemen perawatan diri Psoriasis sangat terbatas. Buku saku sebagai alternatif alat pembelajaran yang memberikan informasi mengenai manajemen perawatan diri dirancang agar mudah dibawa dan digunakan oleh pasien Psoriasis. Buku saku bertujuan mendorong persepsi positif dan keyakinan diri pasien dalam mengelola kondisi Psoriasis. Tujuan studi untuk mengevaluasi efektivitas pemberian buku saku mengenai manajemen perawatan diri terhadap persepsi penyakit pasien Psoriasis. Metode penelitian menggunakan kombinasi desain kuantitatif (kuasi-eksperimental) dilengkapi pendekatan kualitatif. Penelitian melibatkan 30 responden yang didiagnosis medis Psoriasis. Responden dibagi secara merata menjadi dua kelompok kontrol dan intervensi. Kuesioner Persepsi Penyakit (*Brief Illness Perception Questionnaire*/B-IPQ) digunakan untuk menilai persepsi penyakit sebelum dan sesudah intervensi. Uji t-berpasangan digunakan untuk membandingkan skor *pre-test* dan *post-test* pada setiap kelompok. Uji t dua sampel tidak berpasangan digunakan untuk membandingkan perbedaan antara kelompok kontrol dan intervensi. Tingkat signifikansi ditetapkan pada nilai $p < 0,05$. Data wawancara ditranskripsi secara verbatim dan dianalisis secara tematik. Hasil penelitian menunjukkan perbedaan persepsi penyakit antara kelompok kontrol dan intervensi dengan nilai signifikansi sebesar 0,000. Pasien melaporkan jika memiliki pemahaman lebih baik tentang pencetus keluhan dan strategi manajemen efektif untuk mempertahankan kesehatannya lebih baik dengan penyakit Psoriasis. Hal ini menunjukkan jika buku saku merupakan pendekatan edukasi yang efektif dalam memperbaiki persepsi pasien terhadap penyakit Psoriasis. Pemahaman faktor risiko dan teknik manajemen perawatan diri memungkinkan pasien dapat melakukan tindakan pencegahan kondisi *flare-up* dan meningkatkan kesejahteraan hidup.

Kata Kunci: Buku saku, manajemen perawatan diri, persepsi diri terhadap penyakit, psoriasis

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INTRODUCTION

Psoriasis is a chronic illness that causes skin disorders and other body parts due to systemic issues (1). It is characterized by the growth of keratinocytes, leading to thickened patches of skin with scales. The skin condition involves inflammation, influenced by the immune system and environmental factors working together to cause its progression (2). These crucial factors also contribute to the regulation of gene expression. Psoriasis covers a range of symptoms, including both immune aspects, with a slow process between adaptive and innate immune reactions. Chronic plaque Psoriasis primarily involves immunity, while generalized pustular Psoriasis is driven by the immune system and IL 36 autoinflammatory responses. Despite levels of IL1B in both types of Psoriasis, it does not appear to have an impact, with IL1 antagonists generally not proving effective in treating Psoriasis. However, some reports suggest their effectiveness in treating generalized Psoriasis. Different clinical forms of Psoriasis, like inverse Psoriasis, and localized conditions such as Palmoplantar Pustulosis (PPP), show variations in IL 36 responses falling between those seen in Plaque and Pustular Psoriasis. Thus, each subtype of Psoriasis represents a balance between responses and autoinflammatory processes.

Understanding the pathophysiology of Psoriasis stimulates further study in the patient's care. Meanwhile, only 19% of countries have epidemiological data regarding Psoriasis. The population of Psoriasis is about 120.000.000 underserved patients worldwide (3). According to age, Psoriasis is found in about 1% of children, while the occurrence in adults ranges from 0.17% in East Asia to 2.50% in Western Europe. Psoriasis is described to be rarely found in Asia (4). The number of psoriasis cases in Indonesia was observed to be at 0,38% (5). The reason for the occurrence of Psoriasis in Southeast Asia, including Indonesia, could be due to a mix of genetic, environmental, and diagnostic factors. Moreover, healthcare approaches and practice differences could influence underdiagnosis or misdiagnosis in Psoriasis (6). Estimates of Psoriasis prevalence vary across regions, influencing how countries and the global community make decisions regarding public health strategies and understanding the evolution of Psoriasis over time.

Recent research indicates the importance of reevaluating Psoriasis as an isolated disease and recognizing its connection to another chronic disease. Nevertheless, Psoriasis is commonly viewed as a skin condition that can affect individuals without other related concerns. Due to this perception, healthcare providers typically do not routinely screen Psoriasis patients for health conditions like heart disease, cancer, osteoporosis, and certain mental disorders. Meanwhile, Psoriasis frequently occurs before the onset of comorbid diseases, like metabolic syndrome, heart diseases, and autoimmune disorders. Moreover, the mutual connection between Psoriasis and mental health issues pursues the significance of dealing with the emotional aspect of Psoriasis.

Many patients receiving care were discovered to have been exposed to known comorbid risk factors during screenings. Patients require improvement in managing Psoriasis, including understanding risk factors for

conditions and changes. Managing Psoriasis requires treatment due to its nature, which can lead to substantial medical expenses (7). Educational materials must focus on quality and be grounded in theory to enhance the positive perception of self-care management in Psoriasis (8). Previous studies have stated that Psoriasis patients with long-term care often develop a negative perception of their disease (9).

Illness perception describes how people view being sick, influenced by how they think and feel about their health conditions. Adherence to treatment, health mental management, and maintenance of quality of life impact illness perception in the patient (10). Understanding an illness and knowing how to manage care of self are closely linked to illness perception. Research indicates that these perceptions of illness are important in predicting outcomes for health issues like kidney disease and diabetes (11). These perceptions are influenced by demographics, education level, and how symptoms are understood. All affect how individuals cope with and handle their illnesses (12). Previous research conducted at Dr. Saiful Anwar Regional Hospital, Malang, proved that 18 out of 30 patients regarding the need for structured education had a negative perception of the disease. Negative illness perceptions cause patients to fail to adhere to therapeutic regimens, doubt efficacy and perceive excessive drug side effects (13).

Health education enhances people's understanding of health issues, knowledge, attitudes, and behaviors related to staying (14). While traditional methods like leaflets have limitations in providing information, innovative approaches such as pocketbooks have shown promise in improving health education outcomes. However, challenges still need to be addressed in implementing health education programs due to factors like resources, patient awareness levels, differences in access between rural areas, and concerns about patient safety (15). Pocket books have been recognized as tools for education that support learning and information retrieval processes, leading to increased knowledge, attitudes, and skills in promoting health. By utilizing tools like pocketbooks, health educators can help fill gaps in health literacy. Empower individuals to make informed decisions about their well-being (16). These educational initiatives are precious for addressing disparities in healthcare coverage and promoting access to services (17). Moreover, the connection between education and health is vital for reducing inequality and improving wellness (14). Recognizing the impact of education on health outcomes is critical for developing strategies, promoting health, and addressing factors that influence well-being (16).

By providing education opportunities to people and enhancing the effectiveness of healthcare systems, nations can improve health results and reduce healthcare costs (7). Utilizing resources such as pocket guides can significantly enhance health education achievements, boost health knowledge, and encourage healthy habits. Dealing with differences in healthcare availability and empowering individuals through education are measures for attaining health results and supporting general wellness. Based on the previously written background, the author will evaluate providing self-care management education using a pocketbook to improve illness perception, which is expected to improve the quality of life

of Psoriasis patients.

METHOD

Research Design

The research employed a mixed-methods design, combining quasi-experimental and qualitative approaches. The sequence embedded design method, which involves utilizing both quantitative research methods simultaneously with qualitative approach according to Sugiyono. This study utilizes the B IPQ (Brief Index Perception Questionnaire), which includes 9 questions, with 8 response in numbering and 1 response focusing on the patients idea explanation of the cause of Psoriasis. Hence, the descriptive approach used in qualitative design support the numerical data gathered during the evaluation of BIPQ scores. This representation of information based on the patients' opinions and personal experiences also measures the impact before and after the intervention of the pocket book as an educational media on improving patients' perceptions of Psoriasis.

Setting and Samples

The number of psoriasis patients in the dermatovenerology outpatient ward in the General Hospital of Dr. Saiful Anwar Malang has decreased during the COVID-19 pandemic. The population of psoriasis patients numbered 30 people in February – March 2022. Respondents were divided into two groups: intervention and control. The formula two group comparasion showed that the minimum number of respondents in each group was 11. Procedure of collecting sample was purposive sampling technique. The research subject was the psoriasis patients with inclusive criteria as follows: 1. had been diagnosed with medical Psoriasis; 2. was at least 16 years old; 3. was ready to become the subject of this research; 4. was ready to receive and response the interview questions; 5. was fully conscious and generally stable. Exclusive criteria consist of a history of comorbid diseases such as chronic infections, malignancies, and asthma and refusal of the question and interview process.

The total sample attained was 30 patients. Of the 34 Psoriasis patients, four refused to participate. A pocketbook gave the Intervention group self-care management education, while the control group attained health service care as usual in the outpatient ward. Self-care management was delivered using a pocketbook titled "Quality Living with Psoriasis. This pocketbook consists of 3 chapters and consists of 35 pages. Chapter 1 contains an overview of the disease and the intervention for Psoriasis. Chapter 2 contains efforts to control psoriasis risk factors, stress, and pain management. Chapter 3 contains skin care efforts for Psoriasis patients, self-care management for Psoriasis, skincare for Psoriasis, and choosing the proper clothing for Psoriasis.

Measurement and Data Collection

The instrument used for data collection was the B-IPQ (Brief Indeks Perception Questionnaire) which has been translated into Indonesian and had been tested for its validity and reliability. The validity test is carried out using the Pearson correlation method (value correlation ≥ 0.3), while the reliability test uses internal consistency techniques (Cronbach alpha coefficient ≥ 0.7) and chi-square test (p -value 0.05) (19). Data were collected based

on the patient's individual characteristics (age, gender, level of education, type of work, marital status, duration of illness) and the evaluation of illness perception pre- and post-intervention. Participate in this research on an ongoing basis as a volunteer. Data were collected with the assistance of the researcher and student researcher.

Data Analysis

The data analysis was conducted using the SPSS program for Windows version 26.0 with a 95% confidence level and 0.05 error rate (α). The data were analyzed by using the Spearman test. In addition, conducting qualitative analysis, we review the interview findings related to question No. 9 in the questionnaire. This question delves into the factors, behind Psoriasis experienced by patients and how they perceive it both before and after receiving a pocket book as a educational media, for managing Psoriasis care.

Ethical Considerations

Informed consent was obtained from respondents/ participants. Each respondent was advised to fill out an informed consent. The researcher also explained the aim of this study and its significance. The members were informed that their support within the study was deliberate, and they had the right to pull back from the consideration at any time without giving any reason. Patients were guaranteed their confidentiality by coding the information. In addition, all of them were educated that the information were not reused in another inquire about without their authorization.

Ethical approval issued by the Ethics Commission of General Hospital Dr. Saiful Anwar Malang, regarding the Protection of human rights and welfare in medical research, has carefully reviewed this research and approved with the ethical approval no. 400/151/K. 3/102.7/2022 on July 28, 2022.

RESULTS

Univariate Analysis

Univariate analysis aims to describe the characteristics of each variable studied including age, gender, level of education, type of work, marital status, duration of psoriasis illness. In this research, patient characteristics data were analyzed thoroughly descriptively in tabular form percentage.

Table 1. Distribution of Respondents based on age, gender, level of education, type of work, marital status, duration of Psoriasis illness (N= 30 patients)

Category	Amount	%
Age		
17 – 25 years	3	10
26 – 35 years	12	40
36 – 45 years old	3	10
46 – 55 years old	9	30
56 – 65 years old	2	7
>65 years	1	3
Gender		
Man	17	57
Woman	13	43
Type of Work		
Not Yet Working	1	3
Working	29	97

Table 1. Distribution of respondents based on age, gender, level of education, type of work, marital status, duration of Psoriasis illness (N= 30 patients)

Category	Amount	%
Level of education		
S1	9	30
S2	2	7
Elementary school	5	17
Senior High School	10	33
Junior High School	4	13
Marital status		
Not married yet	7	24
Married	23	76
Duration of Psoriasis illness		
≤ 1 year	5	16
>1 year – 2 years	3	10
>2 years – 5 years	3	10
>5 years	19	64

Based on the results of the analysis in Table 1, it shows that the majority of respondents were in the age group 26 - 35 years, namely 12 people (40%), gender of more than half of the respondents were male, 17 people (57%), employment status was more than half of the respondents work as many as 29 people (97%), the last educational status of more than half of the respondents is Senior high school as many as 10 people (33%), marital status more than half of the respondents are married as many as 23 people (76%), the length of time diagnosed with Psoriasis is longer. Of the half of respondents in the range >5 years, as many as 19 people (64%).

Table 2. Illness perception of psoriasis patients in the control and intervention group

Group	Pre Test (Mean±SD)	Post Test (Mean±SD)	P Value
Control	47.07±6.22	37.20±2.98	0.000
Intervention	51.53±2.77	37.20±2.27	0.000

Table 2 shows that the average disease perception score of respondents in the control group before and after control with health workers was 47.07 and 37.20. Perception of the disease based on the score of Psoriasis patients in the control group before carrying out control with health workers was 11 people negative (73.3%) and four positive (26.7%). After control with health workers, the disease perception of Psoriasis patients in the control group was one person negative (6.7%) and 14 positive (93.3%). The average score of respondents' illness perception in the intervention group before being given self-care management education using pocketbook media was 51.53 and 37.20. Perception of the illness based on the score of Psoriasis patients in the intervention group before being given self-care management education was 15 people negative (100%). After being given self-care management education, the disease perception of Psoriasis patients in the intervention group was 15 positive (100%).

The paired sample t-test output results show that the Sig.

(2-tailed) of 0.000 is smaller than 0.05. It can be concluded that there is a difference in the perception of Psoriasis patients between the pre-test and post-test in the control group. The result in the intervention group also showed that there are differences in the perceptions of Psoriasis patients between the pre-test and post-test in the intervention group. In the both group showed that in the post test has a better perceptions.

Theme Analysis in Causal Item of Brief Illness Perception Questionnaire (BIPQ) Scale

The researcher defines the verbal response to item number 9 that has been filled in by the patient in the questionnaire. The perception of the cause of the disease is explained in a type of thematic analysis. Causal item consisted of seven categories was analyzed in qualitative response. Theme 1 was lifestyle category that patient reported lack of sleep time and low physical activity. Theme 2 was psychological causes that patients mentioned the association with specific problem example stress emotional, emotional tension and sensitivity. Theme 3 was natural causes were allergy on food and weather. Theme 4 was working conditions emphasize high physical work loading. Theme 5 was body changes around scars due to scratching of the skin when itching occurs during a Psoriasis flare-up. Theme 6 was environmental factors reported by 4 patients including including extreme weather that different between during the day and night. Theme 7 was other causes that mentioned by patient about economic conditions in lack of financial resources, low salary, inappropriate treatment, the life divorce. Causal dimension of illness perception in Psoriasis. Furthermore, we also analyzed how the causal item were related with self management education using pocket book. The patient reported improvement in understanding and perspective of disease and emotional response. Patients observed by research have different strategy to cover illness consequences. Patient reported manage stress adequately, control the sleep pattern, enhance communication with the spouse to attain their support, and come to health center to conduct regular consultation and treatment.

DISCUSSION

The study has a respondent in the control group, the majority aged 25-35 years old. Additionally, the early elderly respondents (46-55 years) dominated the intervention group. The majority gender of respondents were male (56.7%). The education level dominated in high school at 33.3%. Most of the respondents have a marital status (76.7%). Respondents from the control and intervention groups had a disease duration of >5 years.

The education level dominated research, and data analysis was carried out on the control group of Psoriasis patients; it was found that most of them had negative perceptions before undergoing control with health workers. In this group, patients complete the Pre-test before carrying out health control. The results showed that 11 people (73.3%) had negative disease perceptions, and 4 (26.7%) had positive disease perceptions. The results of the research data analysis showed that 15 respondents in the intervention group (100%) had negative disease perceptions. It can be concluded that the majority of respondents in the intervention group had a negative perception of illness before being given self-care

management education using pocketbook media. This aligns with research conducted by Sari *et al.*, which stated that 18 out of 20 psoriasis patients had a negative perception of illness.

The results of the research and data analysis that was carried out on 15 people with Psoriasis showed that there was an increase in perception after the patient checked with a health worker. The results showed that one person was negative (6.7%) and 14 were positive (93.3%). Meanwhile, research and data analysis that was carried out on 15 people with psoriasis treatment found that there was an increase in perception after patients were given self-care management education through pocketbooks. The results showed that all Psoriasis patients in the intervention group positively perceived the disease, namely 15 people (100%).

The research analysis using the independent sample t-test in the control group shows that the asymp value can also be seen. Sig. (2-tailed) of 0.000 is smaller than 0.05. It can be concluded that there are differences in the perceptions of Psoriasis patients between the control and intervention groups. This also shows that doctor consultation and providing self-care management education to Psoriasis patients have different influences in improving disease perception. The hypothesis can be accepted, namely that there is a positive influence of providing self-care management education using a pocketbook to improve disease perception in Psoriasis patients. Judging from the difference in pre-test and post-test scores between the control and intervention groups. In the control group, the difference in pre-test and post-test scores was 9.87, while in the intervention group, the difference in pre-test and post-test scores was 14.3. This shows that providing self-care management education using pocket books has a higher influence in improving perceptions compared to just controlling health workers.

The results of this study are supported by the results of other research, which states that education can improve preventive behavior, compliance, quality of life, knowledge, disease perception, and self-efficacy (18). Education is an integral part of professional nursing practice standards. Education is an interactive process that encourages learning to increase new knowledge, attitudes, and skills through strengthening certain

practices and experiences (19). Research shows that education can increase knowledge in dealing with signs and symptoms, taking care of oneself, and improving the patient's quality of life (20).

Implication and Limitations

The previous study explains that most psoriasis patients toward barriers and suffer a flare of illness during the pandemic of Covid-19. They feared being infected with Covid-19 when they came to the hospitals, long-distance with the location of the health center, difficulties taking the prescribed medicine in the pharmacy, which is not affiliated with the hospitals, and the side effects of the medicine. They made the patients fail to continue the medication. Structured education makes the concepts of self-care management during the pandemic Covid-19 more relevant (13). One of the education methods was facilitated by the pocketbook. The patient simply learned about self-care management through pocketbooks. The pocketbook was self-care patient need-oriented. The limitation of this research about risk factors included comorbidity diseases, family support, and lifestyle that may have influenced the illness perception not noted.

Psoriasis patients tend to negatively perceive the disease before providing self-care management education in the control and intervention groups. In the control group, 11 people had negative disease perceptions, and in the intervention group, 15 people had negative disease perceptions. Psoriasis patients mostly have a positive perception after being given self-care management education in the control and intervention groups. In the control group, 14 people had positive disease perceptions, and in the intervention group, 15 had positive disease perceptions. There are differences in Psoriasis patients' disease perceptions before and after being given self-care management education in both the control and intervention groups. Self-care management education for psoriasis patients is influenced by using pocketbook media to improve disease perception.

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